



# Priority Setting for HIV and Mental Health in Mexico: Historical, Quantitative and Ethical Perspectives

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**Priority Setting for HIV and Mental Health in Mexico:  
Historical, Quantitative and Ethical Perspectives**

A dissertation presented  
by  
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to  
The Committee on Higher Degrees in Health Policy

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**Priority Setting for HIV and Mental Health in Mexico:  
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**Abstract**

Mexico's innovative health reforms have attracted scholarly attention beyond its own borders, making it a valuable case to study how countries set priorities. This dissertation examines the multifaceted topic of priority setting through a multidisciplinary approach: each of the three papers of this dissertation employs one of three disciplinary perspectives: historical, quantitative or normative. The dual focus on mental health and HIV—two highly stigmatized diseases with almost opposite histories of prioritization—further underscores the social and historical aspects of health priority setting.

Paper 1, “Outrage and Evidence: Julio Frenk and the Politics of Mental Health Advocacy in Mexico, 1968-2006,” examines the recent history of mental health advocacy efforts in Mexico. Tracing the career of Julio Frenk, a contemporary global health leader as well as Mexico's Minister of Health from 2000 to 2006, demonstrates that mental health advocacy moved from a focus on human rights abuses to a statistical-based advocacy that emphasized the burden of mental illness.

Paper 2, “Beyond Universal Treatment Access: A Multi-level Study of Mental Health Care in Public HIV Clinics in Mexico,” represents the first study of the availability and usage of mental health services among HIV+ individuals in Mexican HIV clinics. This paper uses multi-level modeling of a cross-sectional survey from Mexico's National Institute of Public Health to

explore factors associated with patients receiving mental health care. The results indicate that clinic-level factors account for much of the observed variation in mental health care for HIV+ individuals.

Paper 3, “What Magic is there in the Pronoun ‘My’? The Role of Patient and Disease Advocates in Public Deliberations about Priority Setting for Health Policy,” analyzes the risks and benefits of recent, and often controversial, attempts by countries like Mexico to include this specific class of stakeholder in public deliberation for health. Patient participation does bring the risk of bias due to their partiality. However, by drawing on deliberative democratic theory, this paper argues that such partiality confers epistemic advantages to deliberation, such that, if certain procedural and substantive constraints are met, the benefit of their participation may offset the risks.

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### **Frequently used Acronyms:**

**CAPASITS:** Centros Ambulatorios de Prevención e Atención en SIDA e ITS

(Ambulatory Centers for Prevention and Care of AIDS and STIs)

**CENSIDA:** Centro Nacional para la prevención y el control del VIH/SIDA

(National Center for the Prevention and Control of HIV/AIDS)

**CONASIDA:** La Comisión Nacional de SIDA (National Commission of AIDS)

**INSP:** Instituto Nacional de Salud Pública (National Institute of Public Health)

**IMSS:** Instituto Mexicano de Seguro Social (Mexican Institute of Social Security)

**ISSSTE:** Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado

(Institute of Security of Social Services for State Workers)

**PAN:** Partido Acción Nacional (National Action Party)

**PEMEX:** Petróleos Mexicanos (Mexican Petroleum Company)

**PRI:** Partido Revolucionario Institucional (Institutional Revolutionary Party)

**SEDENA:** Secretaría de la Defensa Nacional (National Defense Ministry)

**SIDA:** Síndrome de inmunodeficiencia adquirida (AIDS)

**SSA:** Secretaría de Salud (Ministry of Health)

**VIH:** Virus de la inmunodeficiencia humana (HIV)



## Acknowledgments

As the old saying goes, it takes a village to make a PhD. In my case, at each step, my progress would not have continued without the extraordinary support of my immensely talented, generous and, I must add, patient committee. While diverse in their interests and backgrounds, what unified my committee was their shared excellence in all aspects of mentorship.

From our first conversation in 2006 through the end of the defense in 2013, my adviser and dissertation chair Norman Daniels has modeled the ideal of what a professor should be. Warm, dedicated to his work and devoted to his students, Norm's belief in me helped me reconnect with the work. He was always willing to think any ideas or paper structure through, despite countless previous conversations. Over the years, he showed me, both explicitly and by example, what exemplary philosophical thinking entails. Equally valuable to me was how he invited me to collaborate in his real world projects from my first year, granting me entrance into the world of priority setting, and confirming that ethics can make a difference in the real world. I would not have finished the PhD without Norman's constancy—both in his challenges and his kindness. I look forward to years of collaborations to come.

Allan Brandt's stellar intellect coupled with his unparalleled humanity created a perfectly perfect storm. Just seeing that I had an appointment with Allan on my calendar served as a buoy, as his joy in the process of historical scholarship was so infectious that it worked even vicariously. While pressing me to sharpen the historical analysis at the heart of my writing, Allan remained steadfastly positive about both the value of my project and my abilities to carry it out. He possesses the rarest of pedagogical gifts: the ability to inspire a drive to rise to the occasion. Conversations with Allan always energized me and left me stepping a little more lightly.

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Some of my earliest memories are of my mother, Alice Hunsberger, tapping out her own dissertation long into the night after working all day. When she received her PhD, I was 13 years old and, having witnessed the daily struggles to get to the point, I stood in awe of the accomplishment. That awe has never waned. My mom's profound passion for academia runs deeper than almost anyone else's I know. Her ongoing joy in and tenacious commitment to scholarship has remained steadfast in the face of many obstacles. Luckily, the passion and commitment with which she approaches academia have always characterized her love for me as well. Finishing the PhD without her extraordinary daily, and at times, even minute-by-minute, support would have been simply unthinkable.

Finally, the memory of my father, Angelo Gelpi, has fueled my drive to see this project through to the finish line. During my undergraduate years, he loved embarrassing me by strutting around in his crimson "Harvard Dad" hat. He lived through hell and back, never gave up and never lost his wicked sense of humor. As he always told me during tough moments, "Honey, just forget it, you've got places to go and things to do." Sadly, he didn't live long enough to know that I returned to Harvard for my PhD, but I often have amused myself by imagining him sporting a "Harvard PhD Dad" hat with his trademark twinkle in his eye. I hope that he would be proud of the places I've gone and things I've done.

This dissertation is dedicated to my parents, with all my admiration and all my love.

# **Priority Setting for HIV and Mental Health in Mexico: Historical, Quantitative and Ethical Perspectives**

## **Introduction**

When it comes to health resource allocation, all diseases are not treated equally. No government has sufficient resources to care for all the health needs of its population, and therefore difficult decisions must be made, with some health needs receiving more funding than others. Thus, priority setting occurs everywhere regardless of whether an explicit, public discussion of the need to set limits occurs or not.<sup>1</sup> Given this inevitability of the need to set priorities, in order to achieve a fair and effective health system it is necessary to examine and evaluate health priority setting processes themselves.<sup>2</sup> In order to give a fuller account of how and why some diseases receive higher priority than others, this dissertation focuses on one of the most common disease categories, as well as commonly neglected on the global policy agenda: mental illness.<sup>3</sup>

In Mexico, as is true in many countries worldwide, mental health has remained a much lower priority in the public health budget and agenda than its high burden in the population would

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<sup>1</sup> Norman Daniels and James E. Sabin. *Setting limits fairly: can we learn to share scarce resources*. Oxford; New York: Oxford University Press, 2002.

<sup>2</sup> Norman Daniels. *Just Health: Meeting Health Needs Fairly*. Cambridge; New York: Cambridge University Press, 2008.

<sup>3</sup> In this dissertation, I favor the more colloquial term “mental illness,” but much of the empirical literature will refer to the broader category of neuropsychiatric illness, which includes non-psychiatric, neurological conditions, such as dementia or epilepsy. Due to societal misunderstandings, neurological and psychiatric illnesses are often treated indistinguishably. For example, in Mexico, many patients in psychiatric asylums have development disabilities, including mental retardation, or dementia, rather than a true psychiatric illness.

indicate.<sup>4</sup> The systemic neglect of mental health in global health plans has persisted despite decades of advocacy, both nationally and globally, and despite the rise of evidence that mental illness represents the leading cause of disability worldwide.<sup>5</sup> By contrast with mental health, worldwide, however, HIV has gone from a neglected emerging disease to one of the most highly prioritized diseases.<sup>6</sup> The establishment of and heavy investment in HIV programs, first for prevention and then for treatment, helped transform the landscape of global health policy and practice.<sup>7</sup> Rather than comparing HIV and mental health directly, the first two papers of the dissertation juxtapose an in-depth history of mental health policy in Mexico against a contemporary study of the mental health services available within the country's generously funded national HIV program.

In addition to focusing on one disease area, this dissertation further narrows the broad topic of priority setting in health by spotlighting a single country's experiences. Mexico represents an ideal country in which to study the prioritization of HIV and mental health. As a country new to full democracy, it has undertaken a profound overhaul of its health system in the past decade. Indeed, in recent years, Mexico's innovative health reform efforts have attracted scholarly

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<sup>4</sup> Martin Prince, Vikram Patel, Shekhar Saxena, Mario Maj, Joanna Maselko, Michael R. Phillips and Atif Rahman. "No health without mental health." *The Lancet* 370, no. 9590 (2007): 859-877.

<sup>5</sup> Anne E. Becker and Arthur Kleinman, "Mental health and the global agenda." *New England Journal of Medicine* 369, no. 1 (2013): 66-73.

<sup>6</sup> Allan M. Brandt, "How AIDS Invented Global Health." *New England Journal of Medicine* 368, no. 23 (2013): 2149-2152.

<sup>7</sup> Ibid.

attention far beyond its own borders.<sup>8</sup> While all countries need to set priorities for the allocation of health resources, not all countries acknowledge this inevitability or engage in explicit discussion about how to improve their priority setting processes. In Mexico, however, the process of reforming the overall health system has fueled explicit discussions about how their Ministry of Health can make better decisions about health resource allocation as well as how it can improve the processes by which such decisions are made.<sup>9</sup>

For example, in 2006 the Mexican Ministry of Health began rolling out a new health fund to provide coverage for catastrophic diseases not covered under the standard health budget. Inevitably, the Catastrophic Fund did not have sufficient resources to cover all diseases that would fall under its purview. The priority setting question became: when not all diseases could be fully or, in some cases, partly supported, how should the Ministry make decisions about what diseases to pay for? More precisely, how could the process of selecting which disease to cover avoid cooption by special interests or reliance on arbitrary criteria? In the face of this challenge, Ministry officials engaged in an explicit discussion about how they might establish deliberative processes to make coverage decisions in open, transparent and ethical ways.<sup>10</sup> This example of the Catastrophic Health Fund provides one example of why Mexico is a rich and instructive resource for the study of the social, ethical and political dynamics of priority setting, as well as their implications both for fairness and for population health.

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<sup>8</sup> Richard Horton, “Launching a new movement for mental health.” *Lancet* 370, no. 9590 (2007): 806-806.

<sup>9</sup> Jason Lakin and Norman Daniels, “The Quest for Fairness: a case study of the evolution of Mexico’s Catastrophic Insurance Fund,” Unpublished working paper, 2007.

<sup>10</sup> Jason Morris Lakin, *The Possibilities and Limitations of Insurgent Technocratic Reform: Mexico’s Popular Health Insurance Program, 2001–2006*, PhD diss., Harvard University, 2008.

In Mexico, as in all countries, the prioritization of health raises a host of diverse issues ranging from the technical to social to the ethical. Reflecting the complexities of the problem of health priority setting, studying this topic requires a multidisciplinary approach. For that reason, this dissertation consists of three thematically-related papers, where each paper analyzes the problem of priority setting in health in Mexico from a different methodological perspective: history, quantitative health service research or ethics. The diversity of these methodological perspectives serves to illuminate different facets of the core problem of priority setting. The three papers are organized by their respective focus on past, present and future concerns.

Paper 1, “Outrage and Evidence: Julio Frenk and the Politics of Mental Health Advocacy in Mexico, 1968-2006,” examines the recent history of mental health advocacy efforts in Mexico against a shifting social and political landscape. Focusing on the career trajectory of Dr. Julio Frenk, a contemporary global health leader as well as Mexico’s Minister of Health from 2000 to 2006, provides an analytic lens through which to discern and explain these broader trends. As documented through historical sources, including interviews and analysis of personal archives, Frenk’s approach to public health in general, and mental health in particular, evolved dramatically over these decades—from an advocacy approach centered on activism about human-rights abuses in Mexican asylums to a technocratic approach that emphasized the burden of mental illness in the population through quantitative metrics.

Paper 2, “Beyond Universal Treatment Access: A Multi-level Study of the Availability and Usage of Mental Health Services among HIV+ Individuals in Mexico,” represents the first study of the availability and use of mental health services within the Mexican national HIV program. To date, no existing studies on Mexico have examined either the mental health needs of HIV+



populations or the risks of HIV among those with mental illness. Though official Mexican guidelines recommend that all HIV+ patients receiving care at public HIV clinics should receive mental health care, 80% of patients in the study reported that they had not received such psychological care or counseling. This paper examines what drives that gap by using multi-level modeling to analyze a cross-sectional survey of Mexico's HIV response conducted by the Mexican National Institute of Public Health. The results show that clinic-level factors appear to have a stronger association with whether or not HIV+ patients receive mental health care than personal-level factors. These findings suggest that future policy efforts to improve mental health care within the HIV program should target programmatic issues such as staffing and referral policies, as well stronger efforts to combat stigma in order to decrease barriers to seeking treatment.

In contrast to the empirical examinations of the first two papers, Paper 3 turns to the ethical questions raised by priority setting processes as well as attempts to reform them. This paper, entitled "What Magic is there in the Pronoun 'My'?" The Role of Patients and Disease Advocates in Public Deliberation about Priority Setting for Health Policy," analyzes the potential benefits and drawbacks of including patient and disease advocates in deliberative priority setting for health. Like many countries, Mexico has recently explored increasing democratic participation in policymaking as a means of advancing democracy and integrating civil society into government. One key question is: who should participate in such a process? Yet these stakeholders, both individuals affected by the disease, and patient advocacy groups, pose particular challenges: their special connection to the disease in question expands the range of available evidence, but it also raises the risk of biased participation. Drawing on deliberative

democratic theory, this paper maps the risks and benefits of including stakeholders in deliberations, specifically by framing the practical topic through the lens of the philosophical debate between impartiality and partiality. I argue that there is a proper role for partiality in deliberation in this context, i.e. which under certain procedural and substantive constraints the benefits of stakeholder inclusion may offset the risks.

Though focused on Mexico, the three papers of the dissertation each examine distinct, but overlapping themes in public health that are increasingly of global relevance. The global health community struggles with how to overcome barriers to improving mental health services worldwide. Paper 1, by tracing the recent history of such efforts to advocate for mental health reform in Mexico, provides an unprecedented study of how mental health advocacy operates within a particular social and political context. As Mexican political landscape changed, and as new tools of public health arose, mental health advocates leveraged those developments to further their cause. That the Mexican mental health system remains under-funded relative to WHO's recommendations given the prevalence of mental illness in the population.

The adverse consequences of the perpetual neglect of mental health documented in Paper 1 are illustrated in Paper 2. The results of Paper 2 show that the neglect of mental health in the Mexican health system in general carries over into its highly-prioritized AIDS program, where the mental health needs of the HIV+ population largely go untreated despite the overall high priority granted the national AIDS program. The contemporary focus of Paper 2 raises questions about the future of HIV policy. As HIV/AIDS continues to transform from a universally fatal

disease into a chronic one, the need to manage the health of HIV+ individuals, including the psychosocial burden of living with HIV, will become increasingly salient.

How to make decisions about where resources should be allocated is the topic of Paper 3. In HIV and mental health, the role of civil society groups, including patients and disease advocates, in catalyzing change in policy and practice has been powerful. Although embraced by many in public health, conceptual questions remain about the social and political uses of deliberation to decide on priority setting questions. Paper 3 addresses the skeptical charge that disease advocates and patients should not participate in deliberative priority setting exercises.

The dissertation examines ways in which Mexico and by extension other countries, has, does and *should* develop policies to address the related burdens of stigmatized diseases, such as HIV and mental illness, in its population. The theoretical objectives of the dissertation are to advance knowledge of HIV and mental health policy in Mexico, as well as to propel future research on the ethics and history of public health. The practical objective of the dissertation is to leverage these results to improve public health policies and thereby promote population health.

**PAPER 1**

**Outrage and Evidence:**

**Julio Frenk and the Politics of Mental Health Advocacy in Mexico,**

**1968–2006**

## 1.0. Introduction

In December 2003, the Mexican Secretary of Health held a televised press conference in Mexico City. With reporters from the major television stations gathered around and multiple television cameras recording, Dr. Julio Frenk Mora announced that he had ordered the creation of a new governmental institution, the National Council on Mental Health.<sup>1</sup> Until then, mental health policy in Mexico had fallen under the purview of the Mexican National Council on Addictions.<sup>2</sup> This institutional arrangement, Frenk suggested, had overshadowed many mental health problems due to the political salience of substance abuse and addiction in Mexico.<sup>3</sup> First and foremost, Frenk argued, mental health required its own agency apart from addiction and substance abuse. This new institutional arrangement, he argued, showed recognition of the public health importance of mental health and the resulting need for more active public policy responses.<sup>4</sup>

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<sup>1</sup> Julio Frenk speaking to reporters, December 2003. Archival footage: National Council on Mental Health (*Consejo Nacional de Salud Mental*), Mexico City.

<sup>2</sup> In Spanish, *Consejo Nacional contra las Adicciones*, or CONADIC.

<sup>3</sup> This political salience of substance abuse as a health problem in turn derived from policy concerns over narcotrafficking, which threatened Mexico's economic and diplomatic relations with the United States. Interview with Carlos Rodríguez Ajenjo, July 2010.

<sup>4</sup> Frenk's remarks that day provide his own public interpretation of the rationale for founding. Some have suggested less lofty motivations for the founding of the Council. Because this announcement followed closely after the scandal-driven resignation of Guido Belsasso, Frenk's original appointee for the National Council on Addictions, journalist Jaime Aviles posited that Frenk decided to split up the council into Mental Health and Substance Abuse in order to make Gonzalez Torres, a civil society leader and activist, more politically palatable as a new appointee. See Jaime Avilés, *Los Manicomios del Poder: Corrupción y Violencia Psiquiátrica en*

For Frenk personally, founding this council symbolized his commitment to prioritizing mental health during his six-year term as Minister of Health (2000–2006).<sup>5</sup> More broadly, this act also represented the convergence of several important threads in the history of Mexican mental health. First, Frenk’s arguments for the need for this new council were grounded in statistical data on the burden of mental illness in the Mexican population. Two years earlier, Frenk had led the World Health Organization’s team in preparing the 2001 annual World Health Report, which had focused on mental health for the first time.<sup>6</sup> This report, Frenk now explained, demonstrated irrefutable proof of the profound burden that mental illness imposes on populations around the world and the widespread failure of health systems to provide adequate mental health care. For example, although mental illness represented 15% of the global burden of disease, Frenk noted that on average, countries spend less than one percent of their health budgets on mental health.<sup>7</sup>

Mexico, he claimed, stood out even against this woeful global pattern. The country’s mental health system had failed both in the social abandonment of severely mentally ill patients in institutions and the lack of resources dedicated to community mental health. Indeed, for decades,

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*México* (Asylums of Power: Corruption and Psychiatric Violence in Mexico), Mexico City: Random House Mondadori, 2007.

<sup>5</sup> Interview with Julio Frenk, October 2011.

<sup>6</sup> World Health Organization, *World Health Report 2001: Mental Health: New Understanding, New Hope* (Geneva, Switzerland: World Health Organization,[2001]).

<sup>7</sup> Julio Frenk speaking to reporters, December 2003, archival footage.

Mexico's mental health system had long been criticized as at best, neglectful, and at worst, inhumane.<sup>8</sup> Many of the 15 million Mexican citizens in need of mental health services did not receive it, while the unfortunate individuals confined to antiquated psychiatric facilities languished in nightmarish conditions. The result was a public mental health system that Mental Disability Rights International (MDRI), an international mental health NGO, had condemned in 2000 as the "worst in the world."<sup>9</sup> This glaring gap between the evidence of the Mexican population's need for mental health services and the evidence of the inadequacy of the Mexican mental health system, he declared, demanded decisive policy responses such as the creation of the new council.

Although his own remarks focused on statistics, Frenk's unorthodox choice for the position of Technical Secretary to lead the new council suggested that he still retained a commitment to his rights-based, civil society approach to mental health advocacy. Ms. Virginia Gonzalez Torres

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<sup>8</sup> As will be discussed in Part I, the horrific conditions at the principal national psychiatric asylum, El Manicomio General, popularly known as La Castañeda, had attracted calls for its closure long before it finally shut down in 1968. Guillermo Calderon Narvaez, "Programa De Salud Mental Comunitaria En Mexico," *Boletin De La Oficina Panamericana* (November 1973, 1973), 430-438.

<sup>9</sup> Mental Disability Rights International, *Human Rights and Mental Health: Mexico* (Washington, D.C.: Mental Disability Rights International,[2000]).

In 2001, the *New York Times* quoted the MDRI (now known as Disability Rights International) report in a profile on Virginia Gonzalez Torres's advocacy to shut down Mexico's psychiatric asylums. Michael Winerip, "The Global Willowbrook," *New York Times*, sec. Health, January 6, 2000, 2000.

was a non-physician, a society heiress born into a political dynasty, a longtime human rights advocate focused on mental health reform. Most controversially, she had for decades been a polarizing figure in the insular world of Mexican psychiatry, in which biologically oriented, asylum-based psychiatry had remained the dominant approach. Since the early 1970s, Gonzalez had protested Mexico's abysmal treatment of the mentally ill through a media-savvy combination of muckraking, advocacy work and campaigning. Chaining herself to hospital gates, sneaking into countless psychiatric hospitals, taking surreptitious photographs and movies, she was the incendiary leader of her self-proclaimed "psychiatric revolution" and an advocate par excellence.<sup>10</sup> Described by one of her allies as "an angel and a warrior," her detractors argued that she was unhinged.<sup>11</sup> For those reasons alone, her appointment quickly raised more than a few eyebrows among the psychiatric establishment.

In addition to her general stature as gadfly to mainstream psychiatry and Mexico's mental health system, Frenk's choice of Gonzalez Torres was significant for less personal, more conceptual reasons: it represented the convergence of their two very distinct approaches to health advocacy. Though each had long argued for the importance of mental health as a problem worthy of prioritization in Mexico, and each concurred that the issue had been neglected in Mexico, their approach to framing and responding to the problem had developed into quite different and even conflicting methods and messages. In fact, in an interview, Gonzales admitted that at first she did not get along well with Frenk: "We fought all the time, but then we began to work together. The

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<sup>10</sup> Julio Frenk speaking to reporters, December 2003, archival footage.

<sup>11</sup> Avilés, *Los Manicomios del Poder: Corrupción y Violencia Psiquiátrica en México*.



enemies are the psychiatrists.”<sup>12</sup> While influential, Gonzalez had always approached reform from an outsider’s perspective. By bringing her within the government, Frenk signaled the Fox administration’s embrace of civil society after decades of repression. More specifically, for mental health, appointing Gonzalez Torres represented a way to demonstrate that this Minister of Health would distance himself from the hierarchical, conservative psychiatric establishment and would support Gonzales Torres’ human rights-based approach to psychiatric reform.

When she took to the podium following Frenk’s introduction, the contrast between the rhetorical styles of Gonzales Torres and Frenk became clear. Tearing up and smiling broadly, she declared that that day would be one of hope for the many Mexicans who suffered under the cruelties of the asylum system. Gonzalez Torres, unlike Frenk, cited no statistical data to justify mental health. Instead, in tone and substance, her remarks argued for psychiatric reform on the grounds of human rights. Even more dramatically, she explicitly connected her mission with broader social justice movements. Just as Martin Luther King and Gandhi had fought for justice in their own times, Gonzalez argued, this new council would fight for justice for the mentally ill in Mexico. To demonstrate this patient-centered focus, she invited several clients of her mental health clinics to the podium to address the audience of journalists. By linking her cause to historical freedom fighters, she underscored the moral outrage that drove her own advocacy. Yet despite the surface-level differences between their rhetorical styles, Frenk’s prior remarks about statistical data had served to justify a complementary goal: the importance of making mental health a priority and improving services and care for the mental health needs of Mexicans.

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<sup>12</sup> Interview with Virginia Gonzalez Torres, July 2010.

### **1.0.1. Julio Frenk and Mental Health in Mexican Public Policy**

The press conference in 2003 demonstrates this paper's core argument: that the history of mental health advocacy in Mexico since the 1960s can be characterized by two overlapping eras: the first, a time of human rights-driven protest about abuses in asylums, which was followed in the 1980s by the rise of a more quantitative, evidence-based approach. This paper examines the drivers of this change in strategic approach to mental health advocacy in Mexico across the second half of the 20th Century by tracing shifting understandings of mental health, and as a problem of public policy.

The moral and political continuity between these two approaches becomes clear when considering the career trajectory of Julio Frenk, a contemporary leader in global health as well as Mexico's Secretary of Health from 2000–2006, during the administration of President Vicente Fox Quesada, the first democratically elected government in Mexican history.<sup>13</sup> As documented through in-person interviews, analysis of never-before-accessed personal and archival sources, and other primary and secondary sources ranging from the 1970s to the early 2000s, Frenk's conceptual and evidentiary approach to health in general, and mental health in particular changed dramatically and in ways consistent with broader intellectual currents.<sup>14</sup>

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<sup>13</sup> For more on the political transformation of Mexico before and after the election of 2000, see David A. Shirk, *Mexico's New Politics: The PAN and Democratic Change* (Boulder, Colo.: L. Rienner, 2005), 279.

<sup>14</sup> J. Trostle, M. Bronfman and A. Langer, "How do Researchers Influence Decision-Makers? Case Studies of Mexican Policies," *Health Policy and Planning* 14, no. 2 (Jun, 1999), 103-114.

As a medical student in the 1970s, Frenk drew directly from the activist script as he participated in exposés of conditions in psychiatric asylums of Mexico. By the early 1980s, after pursuing advanced training in public health, Frenk's interests and career had begun and would continue to widen in scope. He pioneered new research methodologies that re-imagined health in quantitative terms, an epistemological shift which opened up new understandings of mental health and thereby expanded the possibilities for research-driven policy innovations. Due to his ever-growing global influence during these years, this broad evolution in his thinking and his activities reflected and drove changes in many spheres of health: the Mexican mental health system, the Mexican political landscape, and global health writ large.

This narrative demonstrates broader continuities and conceptual linkages between the human rights focus of the 1970s and the statistical emphasis of the 1980s and 1990s, a shift that might otherwise appear to be a complete rupture in paradigm. Indeed, despite this broad shift toward quantitative methods and forms of policy argumentation, close examination of Frenk's career during these years demonstrates his sustained commitment to the sociopolitical dimension of mental health and mental health policy. Thus, examining the progression of Frenk's career, ideas and initiatives in historical context—by considering personal, regional, political and global factors—reveals otherwise hidden aspects of the change in the social and political meaning of mental health as a problem of Mexican public policy across these years.

This paper makes several contributions. Within the small field of histories of Mexican psychiatry, most studies focus on the period surrounding the 1910 founding of the General

Asylum and its subsequent decline. Thus, as a more recent history, this paper provides an alternative look at the determinants and obstacles to psychiatric reform in Mexico set within the contemporary landscape of shifting political and social factors. As a historical study of an important disease category for policy, this paper also contributes to the growing body of work on priority setting in health, in which historical perspectives are relatively uncommon.<sup>15</sup> By examining this topic through a historical lens, the critical role of historical contingencies, such as key personalities and methodological developments in public health policy are illuminated.

Though the core argument of this paper is that the arc of Frenk's career exemplifies the changing landscape of mental health advocacy and policy in Mexico, he himself remains of course, not just an analytic lens but also a unique individual with his own background, temperament who both influences and influenced by historical constraints within a specific sociopolitical context. Specifically, Frenk's outsized presence in this narrative reflects an argument both about his influential role as a visionary in global health and about his critical and evolving influences in shaping mental health policy in Mexico. In addition, the elite nature

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<sup>15</sup> Some examples of non-historical studies of health priority setting include: Sofia Gruskin and Norman Daniels, "Justice and Human Rights: Priority Setting and Fair Deliberative Process," *American Journal of Public Health* 98, no. 9 (09, 2008), 1573-1577.; S. L. Sibbald et al., "Evaluating Priority Setting Success in Healthcare: A Pilot Study," *BMC Health Services Research* 10 (May 19, 2010), 131.; D. Wikler, "Why Prioritize when there Isn'T enough Money?" *Cost Effectiveness and Resource Allocation : C/E* 1, no. 1 (Feb 26, 2003), 5.

of psychiatry in Mexico also makes the choice to focus on one leader, rather than grassroots organizers, substantively sound.<sup>16</sup>

### **1.0.3. Structure of the Paper**

The paper proceeds in three sections that move chronologically from the early 1970s through 2006. Together they analyze Frenk's role in shaping Mexican psychiatric reform movements against the backdrop of broader changes in health and society over that time.

**Part 1** details the state of the Mexican mental health system in the early 1970s when Frenk came of age as a medical student. Worldwide, the 1970s were a time of crisis in psychiatry. Much has been written about the influence of an international set of psychiatric critics commonly referred to as “antipsychiatrists,” which includes figures such as Thomas Szasz, Franco Basaglia and others—in their own countries. However, less scholarship has addressed their influence beyond the developed world, and no known historical studies of antipsychiatry in Mexico exist (to my knowledge). As a medical student, Frenk passionately championed antipsychiatric ideas through print and protest in Mexico as a means to compel reform of Mexico's psychiatric asylums. In so doing, he simultaneously drew on international intellectual trends and adapted them to the local context.

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<sup>16</sup> For more on the elite-dominated nature of Mexican health policymaking, see Trostle, Bronfman and Langer, *How do Researchers Influence Decision-Makers? Case Studies of Mexican Policies*, Vol. 14 (ENGLAND: , 1999), 103-114.; Jason Morris Lakin, *The Possibilities and Limitations of Insurgent Technocratic Reform : Mexico's Popular Health Insurance Program, 2001--2006*, 2008), 315 leaves.

**Part 2** documents Frenk's career through the 1980s and 1990s to show how his work on population-level health issues helped to create the intellectual foundation for a change in the perception of mental health as a global policy problem, and later, underscored his renewed focus on health reform. In contrast to his rights-based health student activism of the 1970s, his career in the 1980s and 1990s took a more academic, empirical and quantitative turn. Although Frenk did not focus on mental health during this period, this section demonstrates that his broader work in economic and epidemiological studies, as well as his leadership positions in Mexico and the WHO, eventually contributed to global recognition of mental health as a global health problem.

**Part 3** details Frenk's tenure as Minister of Health in Mexico (2000–2006), with a focus on the impact of his work on mental health.<sup>17</sup> The politics of mental health policy proved to be a considerable impediment to reform. Although successful in achieving major health reform, specifically the passage of a landmark health insurance scheme called *Seguro Popular*, by the end of 2006, when Frenk's term as Minister was completed, the Mexican mental health system remained one largely grounded in large psychiatric hospitals and asylums, as it had been in the 1970s. This historical narrative illuminates the reasons for this continued failure to achieve psychiatric reform in Mexico.

#### **1.0.4. Why Mexico's Mental Health System Matters to Global Health**

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<sup>17</sup> Julio Frenk et al., *Economía y Salud: Propuestas para el Avance del Sistema de Salud en México*, final report, Mexico City: Fundación Mexicana para la Salud, 1994.

Mexico is surely no model for successful mental health system reform. Yet it warrants scholarly attention precisely for that reason. Where case studies of disease advocacy exist, they tend to focus on success stories, such as how HIV/AIDS rose from an invisible social ill to the top of the public health agenda through a confluence of advocacy, politics and science.<sup>18</sup> In addition to studying cases of successful disease prioritization, the less successful examples of such attempts, such as that of mental health in Mexico, provide important lessons that should not be ignored. In fact, such cases may provide richer, or at least complementary, insight into the myriad reasons that mental health that finds a place on the agenda or not.

As many have noted, rigorous data on the vast burden of mental illness alone has failed to yield proportionately robust reforms in many countries.<sup>19</sup> One lesson of this study then is that predicting the impact of evidence on successful advocacy, or predicting the relationship between data and action can be difficult. Yet for many public health professionals, including Frenk, their ideal vision is that research will cleanly inform policymakers who will act on that research.

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<sup>18</sup> Mental health advocates are explicitly searching for lessons in the history of AIDS activism that could help in their own efforts. For more on the rise of HIV/AIDS as a public policy priority, see Allan M. Brandt, "How AIDS Invented Global Health," *N Engl J Med* 368, no. 23 (06/06; 2013/08, 2013), 2149-2152.

Randall M. Packard, ed., *Emerging Illnesses and Society: Negotiating the Public Health Agenda*, Baltimore: Johns Hopkins University Press, 2004, p. 420; Steven Epstein, *Impure Science : AIDS, Activism, and the Politics of Knowledge*, Vol. 7 (Berkeley: University of California Press, 1996), 466.

<sup>19</sup> Anne E. Becker and Arthur Kleinman, "Mental Health and the Global Agenda," *New England Journal of Medicine* 369, no. 1 (2013), 66-73.; Vikram Patel, Benedetto Saraceno and Arthur Kleinman, "Beyond Evidence: The Moral Case for International Mental Health," *American Journal of Psychiatry* 163, no. 8 (August 1, 2006), 1312-1315.

Many other of course factors intervene. As Frenk himself wrote in 1993, “health is a crossroad...where biological and social factors, the individual and the community, and social and economic policy all converge.”<sup>20</sup> By detailing this convergence, historical analyses of public policy problems can illuminate the oft-overlooked role of how social, cultural and political contingencies shape health policies. For Frenk and mental health, such factors influenced his own recognition of the problem of mental health, as well as the range of ways that he responded to this problem over three decades, and the subsequent reception those actions had in Mexico.

Beyond Mexico, this paper raises broader questions of current interest about priority setting for health. The narrative constructed in this paper points to a future research agenda aimed at better understanding how various advocacy approaches to disease prioritization differentially impact the public health agenda across changing social and political contexts. Further, the case of mental health in Mexico raises a host of theoretical issues about the possibility of pluralistic definitions of evidence and their comparative functions in disease advocacy. Such questions include: how can advocates generate political will to reform policies, particularly for stigmatized conditions? Is there a coherent division between evidence-driven advocacy and political activism? How do public health problems get identified and then acted upon? What counts as evidence and what are legitimate uses of evidence in politics and policymaking? This study aims to illustrate the importance of such questions, even if complete answers remain elusive.

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<sup>20</sup> Julio Frenk, "The New Public Health," *Annual Review of Public Health* 14, no. 1 (1993a), 469-490.



Beyond mental health, this case also illuminates critical issues for global health systems in general. As nations develop and world populations age, the global disease burden will continue the shift already underway from primarily infectious toward primarily non-communicable and chronic diseases. More than ever, countries will have to confront the question of how they will respond, what policies they will adopt and how social values translate into public health systems. Thus, the specific, local story of mental illness in Mexico has a broader significance: it reflects the coming wave of problems that will demand action as well as attention from health systems worldwide.

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At the press conference in Mexico City that December day in 2003, Gonzalez Torres concluded her remarks with a flamboyant gesture of triumph. As she returned to her seat, Frenk rose and the two embraced. After posing for a few photographs, they closed the press conference. Arm in arm and smiling, the two left the stage and moved to an adjacent hallway. Together they fielded reporters' questions, including inquiries about the Council's plans for increase resources for mental health and how it would implement new models of care across the country. For those gathered in the conference room, who had long pressed for change to Mexico's mental health system, it was a day of hope and of the promise for long-awaited change to a system long deemed to be broken and even dangerous. Yet real change would prove more difficult to achieve.



## **PART I**

### **Psychiatry, Power and Politics in Post-Asylum Mexico:**

#### **Julio Frenk as a Medical Student, Late 1970s**

##### **1.1. The Political Awakening of Julio Frenk**

Julio Frenk came of age in Mexico City in the early 1970s. His decision to enter medical school and his wish to train as a psychiatrist reflected the general foment around the field during this time. Just as the counterculture movements were sweeping the world in the late 1960s, in psychiatry similar challenges to traditional authority arose and sought to dismantle old ways. Worldwide, historic custodial asylums came under attack for abuses and neglect, antipsychiatry grew into a formidable theory that influenced practice and some countries took steps to shutter their asylums and establish community-based mental health programs in their place. Reflecting these broader trends, but marked by its own politics and culture, Mexican psychiatry in the 1970s was in a state of crisis.

In Mexico, 1968 had witnessed both the closure of the General Asylum “La Castañeda” and the fatal student riots at the 1968 Olympic Games in Mexico City. Though seemingly unrelated, the two events both drew upon a mounting outrage at Mexico’s authoritarian political system, including the university and the workings of its medical faculty. More specifically, the student protests at the Olympics set a model for Mexican student activism that Frenk would adopt a few years later to protest psychiatric abuses. Despite the optimism that these uprisings would usher in

change, neither event seemed to change much either in terms of Mexican society or psychiatry.<sup>21</sup> In the words of one medical student writing 15 years later, “the sad thing is...the structure of La Castañeda has remained unaltered: between that hospital and the smaller ones [“las granjas”; in English, “farms”] lies a continuity of procedures, organization, violence and ideology.”<sup>22</sup> By contrast, those in positions of authority in psychiatry remained authoritarian, hierarchical and convinced that the field was apolitical due to its grounding in the scientific method.<sup>23</sup> This establishment psychiatry would soon be shaken: these two events revealed that cracks had begun to show in the walls of this insular world.

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<sup>21</sup> Indeed, the students’ hero, Italian antipsychiatrist Franco Basaglia, had already noted the class tension that arose when medical students, usually from the social elite, took up the cause of patients in psychiatric asylums, who typically came from the lower classes. The medical students used their social privilege to demand change, while often not recognizing the impassable divide separating them from their patients. Franco Basaglia, Nancy Scheper-Hughes and Anne Lovell, *Psychiatry Inside Out : Selected Writings of Franco Basaglia* (New York: Columbia University Press, 1987a), xxviii, 318 p.

<sup>22</sup> By contrast, the psychiatric establishment who had overseen the closure of the asylum did not share the student’s bleak view. In 1973, Guillermo Calderón Narváez boasted to an international journal that “in recent years, Mexico has totally transformed its public mental health programs.” Calderon Narvaez, *Programa De Salud Mental Comunitaria En Mexico*, 1973), 430-438.

<sup>23</sup> For an example of psychiatry’s self-proclaimed commitment to science as a badge of disciplinary legitimacy, see this 2010 profile of Dr. Rafael Velasco, one of the more powerful psychiatrists in 1970s Mexico, in Jorge Sánchez-Mejorada, “La Psiquiatría Mexicana En Deuda: Una Semblanza De Rafael Velasco Fernández,” *La Palabra Y El Hombre: Revista De La Universidad Veracruzana* Number 11, no. Tercera Epoca (2010).

The closure of the Grand Asylum (El Manicomio General), more popularly known as “La Castañeda,” mirrored more profound changes that occurred during this period. Just as the 1960s movements challenged many establishment institutions across the world, in Mexico during this period, medical students developed a passion for change that took aim at the hierarchical world of Mexican psychiatry. In the 1970s, the younger generation of Mexican medical students was soaking up the youth-led counterculture that swept the world. These broader forces gave momentum to their dawning vision of politicized perspectives on medicine, and psychiatry in particular.

While the older generation of psychiatrists rejected or failed to comprehend the younger generations’ concerns, they would soon be forced to respond. According to older guard Mexican psychiatrist Carlos Pucheu, looking back in 1990, the sea change that was developing among medical students led to the “clear politicization of psychiatric ideas, with the facile labeling of individuals into ‘friends’ or ‘foes,’ accompanied by doctrinal polarization and militant attitudes.”<sup>24</sup> More supportive observers called this movement “the psychiatric revolution.”<sup>25</sup>

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<sup>24</sup> Renato D. Alarcón, *Identidad De La Psiquiatría Latinoamericana : Voces Y Exploraciones En Torno a Una Ciencia Solidaria*, 1.th ed. (México, D.F.: Siglo Veintiuno Editores, 1990), 670 p.

<sup>25</sup> Virginia Gonzalez Torres calls her activism “the psychiatric revolution.” This revolutionary language for psychiatric reform in Mexico began earlier. For example, see Encuentro Internacional de Alternativas a la Psiquiatría, Franco Basaglia and Sylvia Marcos, *Antipsiquiatría Y Política : Intervenciones En El Cuarto Encuentro Internacional De Alternativas a La Psiquiatría (Cuernavaca/1978)*, 1a en castellano. ed., Vol. 57 (México: Extemporáneos, 1979), 247 p.

This section reconstructs the Mexican mental health system at the time that Julio Frenk, as a young future leader, awoke to its shortcomings. Against this background of a branch of medicine in crisis, Frenk began to recognize, and then to advocate, for changing the mental health care system in Mexico. This section also documents a largely untold story about how international practices, theories and trends influenced Mexican psychiatry during this period. In countries with well-documented movements of antipsychiatry or psychiatric reform (i.e., United Kingdom, United States, France, Italy and Spain), little has been written about the history of psychiatry in Mexico following the Grand Asylum's closure.

This gap in the historical record may exist because Mexico never successfully transformed its psychiatric establishment (as Italy did in 1978) or because Mexico did not produce leading theorists of the antipsychiatric movement. Regardless, the result has been little investigation about how the well-known global movement toward psychiatric reform and deinstitutionalization played out in a Latin American country attuned to and responsive to changes in the “advanced societies” of Europe and the United States. Despite long being politically free of colonialism, Mexico's psychiatrists revealed a continued preoccupation with colonial legacy through their continued intellectual and clinical dependence on these other countries, a frustration that fueled some of the internal debates. This section reveals the strong influence of international antipsychiatric thought on the Mexican students as well on general interest among educated elites. The understanding of these theories was necessarily refracted through the lens of the local Mexican context.

Specifically, this analysis shows that Frenk's days of medical student activism drew upon two sources: he became fascinated by the study of anti-psychiatric reformers abroad, whose theories helped provide a framework for understanding his first-hand experiences with the horrors of the Mexican psychiatric facilities. By extension, these experiential and theoretical sources led him to two types of activist reform: first, conducting exposés that publicized the conditions in the asylum and secondly, writing theoretical essays that deployed antipsychiatric theories as weapons with which to attack the psychiatric establishment.

### **1.1.2. Julio Frenk in Medical School: Old Guard Meets the Vanguard**

Julio Frenk entered medical school at the country's flagship university, the National Autonomous University in Mexico City (UNAM). He had strong interests in mental illness and was considering becoming a psychiatrist. Soon, Frenk found himself taught by an older generation of psychiatrists who had trained in a way that seemed antiquated to the younger generation. Just as in many countries, in the late 1960s and early 1970s the Mexican university's traditional, biological and apolitical approach to medical education clashed with students' desire to discuss medicine's connection to their political views.<sup>26</sup> The generation of medical school faculty, and specifically psychiatry professors, in charge when Frenk entered medical school had been trained in a very different environment, both academically and

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<sup>26</sup> The historical literature on medical student activism in Mexico during this period is slight. For a related take on medical student activism in the United States, see Naomi Rogers 1958-, *An Alternative Path : The Making and Remaking of Hahnemann Medical College and Hospital of Philadelphia* (New Brunswick, N.J.: Rutgers University Press, 1998), xi, 348 p.

socially. These professors, mostly born in the 1920s, held strong views about what psychiatry ought to be, about how to adjudicate between the two dominant approaches at the time: biological and psychoanalytic, and about the best direction for Mexican psychiatry to advance in the future.<sup>27</sup>

The world of psychiatry in Mexico was so small in those days that an inner cadre of several individuals dominated the field. This small group—led by Ramon de la Fuente, Guillermo Calderón and Rafael Velasco, among others—rotated through top positions in academia, government and leadership positions at hospitals and asylums. As Carlos Pucheu, one of these leading Mexican psychiatrists later described, Mexican psychiatry then existed in a state of “intolerance” to different ideas, even mainstream ones. Each professor or hospital superintendents ruled over his fiefdom by insisting on his pet school of thought and rejected outright any discussion of others.<sup>28</sup>

These psychiatrists, who in later decades would become Frenk’s teachers, represented the old guard whose antiquated and inhuman methods—including insulin-induced comas, lobotomies and shackling patients in chains—Frenk and the others would rail against. In their own youthful period of medical and psychiatric training in the 1950s, however, many of their reflections echo those made by Frenk years later. At different times, both the older group and

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<sup>27</sup> Note that neither of these two dominant approaches was political, a fact that would change with the rise of the student-led antipsychiatric movement.

<sup>28</sup> R. G. Alarcon, "Hacia Una Identidad De La Psiquiatra Latinoamericana," *Bulletin of the Panamerican Health Organization* (August, 1976), 109-121.



the young reformers railed against the triumph of dogma over reason in psychiatry, the neglect of patients in the asylum, and the lack of a public health perspective in psychiatry. Where they departed, however, was in the fact that the older psychiatrists called for integrating a social (but not political) conception of humanity along with the dominant biological focus of the time. In other words, while they acknowledged that human psychology developed in the context of social relations, they rejected the antipsychiatric critique that the very concepts of mental illness reflected and reinforced state control over the lower classes. Rather than engage in this debate, in their writings, most traditional psychiatrists agreed that the key battle in those days was between the “organicists” and the “psychoanalysts.”

The most distinguished Mexican psychiatrist of that time was Ramón de la Fuente Muñiz. In an autobiographical essay about his career published posthumously several months after his death in 2006, de la Fuente described “the academic and scientific landscape of psychiatry of Mexico” when he entered the profession in the 1950s as “quite limited.”<sup>29</sup> For that reason, he explained, Mexican psychiatry necessarily drew heavily on work pioneered by European and US researchers, a trend that continued into Frenk’s day.

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<sup>29</sup> Ramón de la Fuente Muñiz, Ramón, "Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría," *Letras Libres: Edición México* 92 (August, 2006, 2006), 52-55.

Once in medical school, de la Fuente complained that in “1956 the education of a physician at the Faculty of Medicine at UNAM was notoriously technical and left aside the human dimension of clinical problems.” Another prominent psychiatrist, Guillermo Calderón Narvaez, wrote that the 1950s were “without a doubt, the most important for the development of psychiatry at the world level, since psychopharmacology was born during this era, and therefore the possibility of treating the ill with it, just like other branches of medicine.”<sup>30</sup> Rather than remaining on the fringes of medicine, psychiatry would become integrated into biomedical therapeutics. To counteract what he viewed as psychiatry’s limited, overly technical nature that ignored the human dimension, de la Fuente proposed that a new topic—medical psychology—become part of the core medical curriculum at UNAM. This new field, he hoped, would serve as “the disciplinary bridge between biomedicine and sociomedicine: the necessary framework for a humanistic orientation.”<sup>31</sup> Building on this foundational work on medical psychology, in 1959 de la Fuente published *Medical Psychology*.<sup>32</sup> De la Fuente’s specification of this new humanistic focus notably did not include the political dimension of psychiatric nosology championed by the antipsychiatrists and his students.

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<sup>30</sup> Calderon Narvaez, *Programa De Salud Mental Comunitaria En Mexico*, 1973), 430-438.

<sup>31</sup> de la Fuente Muñiz, Ramón, *Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría*, Vol. 92, 2006), 52-55.

<sup>32</sup> The editors of De la Fuente’s 2006 article note that indeed, *Medical Psychology* was used in practically all medical schools in Latin America. Its two editions have had more than 30 reprintings.

As did the younger generation of medical students, the older generation of psychiatrists had also found themselves appalled at the conditions in the General Asylum, La Castañeda. In his third year of medical school, de la Fuente was invited to visit La Castañeda Asylum. Recalling this experience in 2006, over 50 years later, he still expressed horror at what he saw: “the image of the patients ragged and dirty, burned by the sun, sharing the scarce food in the patios of the clinic, was for me painful and traumatic. I believed that situation was unacceptable.”<sup>33</sup>

Similarly, Dr. Guillermo Calderón Narvaez, who headed the asylum in the mid-1960s, found the conditions so horrific that he strategically planned to get the asylum condemned by the Secretary of Health itself. Looking back on this episode in 2002, he described how he purposefully exposed a visiting high-level Secretary of Health official to parts of the asylum so appalling they were usually hidden from visitors. Calderón’s goal of such exposure was to shock the official into taking governmental action to address the problem.<sup>34</sup> The mission succeeded, and Operación Castañeda began, which would eventually in 1968 close the notorious asylum and lead to the

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<sup>33</sup> de la Fuente Muñiz, Ramón, "Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría," *Letras Libres: Edición México* 92 (August, 2006, 2006), 52-55.

<sup>34</sup> Guillermo Calderón Narváez, *Las Enfermedades Mentales En México : Desde Los Mexicanos Hasta El Final Del Milenio*, 1a, mayo 2002 ed. (México, D.F.: Editorial Trillas, 2002), 164 p.

construction of the Las Granjas, smaller facilities designed and constructed to be more humane (but which quickly deteriorated into the state of neglect of their predecessor).<sup>35</sup>

Thus, even by their own words, those psychiatrists whom the medical students condemned as repressive and opposed to reform had criticized Mexican psychiatry on many of the same grounds. Indeed, the critiques that Frenk would level against the asylum were not substantively different than those that their elders had made two decades earlier. They just did so in a much more aggressively, anti-authoritarian, politicized manner that defied the hierarchical nature of Mexican psychiatry at the time.

Frenk charged Mexican psychiatry with being blind to the social and political dimensions of psychiatric illness. This resulted from economic incentives to focus on private practice. In 1973, Dr. Guillermo Calderón, the psychiatrist who had run and overseen the closure of La Castañeda, complained that the rise of Freudian psychoanalysis had incentivized psychiatrists “to abandon the asylums and take refuge in their private practices.”<sup>36</sup> The human resource shortage compounded the problem. In 1973, Calderón wrote that in the mid-1960s, Mexico had 30,000 doctors, two psychiatric nurses and five psychiatric residents but only 400 psychiatrists, fully

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<sup>35</sup> Cristina Sacristan, "Ser Or no Ser Modernos: La Salud Mental En Manos Del Estado Mexicano, 1861-1968," *Revista Espaco Plural* XI, no. 22 (Enero-junio 2010, 2010).

<sup>36</sup> Calderon Narvaez, *Programa De Salud Mental Comunitaria En Mexico*, 1973), 430-438.

half of whom worked in private, largely urban practices.<sup>37</sup> Public institutions and the poor patients housed within them languished, while most psychiatrists focused on giving time-intensive therapy to the paying elite of Mexican society.<sup>38</sup> According to this powerful critique, psychiatry, as did most of organized medicine, reinforced the vast social inequalities pervasive in Latin America persisted (this critique that was echoed by critics of psychiatry around the globe).

For instance, in 2002 Calderón argued that one cause of “the alienation of psychiatry” was psychiatry’s focus on private practice rather than public health system, and individual psychopathology rather than social contributions to emotional suffering.<sup>39</sup> In Mexico, as elsewhere, psychiatry remained quite distinct from public health, which limited successful implementation of population-wide reform efforts.<sup>40</sup> Another major theme in the writings of this

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<sup>37</sup> Ibid.

<sup>38</sup> Guillermo Calderon Narvaez, "Programa De Salud Mental Comunitaria En Mexico," *Boletin De La Oficina Panamericana* (November 1973, 1973), 430-438.

<sup>39</sup> Calderón Narváez, *Las Enfermedades Mentales En México : Desde Los Mexicanos Hasta El Final Del Milenio*, 1a, mayo 2002 ed. (México, D.F.: Editorial Trillas, 2002), 164 p.

<sup>40</sup> This systemic neglect of psychiatry was reflected in the historical configurations of its institutions. For example, although the current Mexican Ministry of Health was established post-WWII, a separate Department of Mental Health within the Ministry was only founded in 1959.

older generation of psychiatrists concerned the professional isolation of psychiatry. Many of the psychiatrists' self-critiques in the 1950s and 1960s centered on concern about their own quest to make psychiatry a legitimate branch of medicine. Psychiatry's professional distance from other branches of medicine and public health has been advanced as one reason that mental illness has failed to become a major agenda item on the international stage.<sup>41</sup>

The scientific method, as understood by the psychiatrists, called for a Popperian falsificationist model in which scientific hypotheses could be disproven by evidence. This approach seemed crucial for the transformation of psychiatry. Dr. Rafael Velasco, who would in 1977 become the main antagonist of the medical students, declared himself to be a devotee of Popper and Bertrand Russell, because Velasco declared, Russell had committed himself to always place "reason above dogma."<sup>42</sup> Another way that psychiatry would become more scientific, these psychiatrists argued, would be to strengthen its connection to the neurosciences. As Calderón described in 2002, the 1950s saw the rise of psychopharmaceuticals that offered the hope of actually effectively treating psychiatric patients.<sup>43</sup> Proponents of these developments believed

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<sup>41</sup> Calderon Narvaez, *Programa De Salud Mental Comunitaria En Mexico*, 1973), 430-438.

<sup>42</sup> Sánchez-Mejorada, *La Psiquiatría Mexicana En Deuda: Una Semblanza De Rafael Velasco Fernández*, Vol. Number 11, 2010).

<sup>43</sup> Writing in 2002, Calderón uncritically pointed to the emptying of the psychiatric institutions through the 1970s as evidence that the right medications transformed chronic patients into

that they underscored their own vision of science and medicine as politically neutral, objective and powerful. These developments made it easier for these psychiatrists to reject the emerging theories of science as socially embedded and value-laden.<sup>44</sup> The politically charged approach that Frenk and the medical students championed in the 1970s was equally a non-starter.

The perspectives of the psychiatrists who were in positions of authority in the 1970s reveals that, during their earlier own training and early years of practice in the 1950s and 1960s, they viewed their own efforts as ones central to psychiatric reform and progress. In fact, many of their substantive complaints about the system anticipated those that their later students such as Frenk would make a few decades later. However, where the two generations diverged is in the former's focus on positioning psychiatry as scientific field in the sense of an objective and neutral practice, their quest to develop institutions of cutting edge research and teaching to position Mexico as a leader in the global field, and the single-minded enthusiasm for the transformational promise of the biological research and treatments. They rejected "dogma" as antithetical to their scientific method. Though they referred to the social aspects of psychiatry, this concept did not include any recognition of political dimensions of psychiatry (such as how

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citizens who would function outside the walls of the asylum. Calderón Narváez, *Las Enfermedades Mentales En México : Desde Los Mexicanos Hasta El Final Del Milenio*, 1a, mayo 2002 ed. (México, D.F.: Editorial Trillas, 2002), 164 p.

<sup>44</sup> Thomas Kuhn's landmark publication of *The Structure of Scientific Revolutions*, which advanced a more social theory of scientific change than the Popperian model, would be published in 1962. Thomas S. Kuhn et al., *The Structure of Scientific Revolutions*, Vol. . 2, no. 2 (Chicago: University of Chicago Press, 1962), xv, 172 p.

institutionalized populations came almost exclusively from the lower classes), not to mention the broader fields of science and medicine. This rejection of the possibility of a political aspect to psychiatry would become a critical complaint among medical students in the early 1970s, who sought to highlight how class and social status permeated all aspects of psychiatric practice, including who was diagnosed as mentally ill and how they were treated.

### **1.1.3. The Medical Students and the Politicization of Psychiatry**

The medical school curriculum at UNAM in the 1970s focused on traditional subjects such as anatomy and physiology. For example, although de la Fuente's course on medical psychology was extremely innovative when he started it in 1959, it nevertheless reflected the individualistic and biological focus characteristic of Mexican psychiatry (and much of international psychiatry) in the late 1960s. Similarly, although the students were taught psychoanalytic theory—Erich Fromm had lectured annually at UNAM for five years between 1961 and 1965—the psychoanalytic training the students received did not engage with approaches that tackled the social and political aspects of theory, such as how individual's psyche develops within its sociopolitical world.<sup>45</sup>

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<sup>45</sup> Interview with Julio Frenk, October 2010. His perspective on the curriculum finds validation in the accounts of his professors. See Velasco's and De la Fuente's accounts of teaching psychiatry at UNAM in the late 1960s to early 1970s. de la Fuente Muñiz, Ramón, *Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría*, Vol. 92, 2006), 52-55.; Sánchez-Mejorada, *La Psiquiatría Mexicana En Deuda: Una Semblanza De Rafael Velasco Fernández*, Vol. Number 11, 2010).



Upon realizing that their biologically oriented coursework would not teach them about burgeoning ideas in psychiatry, Frenk and a group of fellow students grew disenchanted with the school's curriculum.<sup>46</sup> Since their professors would not engage with these arguments during class time, Frenk and a group of fellow students began to organize a self-taught reading group that focused on discussing contemporary work on social and political aspects of psychiatry, including the new movement called "antipsychiatry" taking rise in Europe and the United States. Every Friday, after their classes in anatomy and physiology, the students would meet at a local café to talk through and debate the exciting new theories and approaches about psychiatric reform from countries "to their North and across the sea."<sup>47</sup>

Despite the unity implied by the umbrella term, "antipsychiatry" did not consist of a single idea, a unified movement, or even a self-declared set of leaders.<sup>48</sup> Rather, the term antipsychiatry, first coined in 1968 by British psychiatrist David Cooper, eventually came to be applied to an international set of theorists (usually psychiatrists from Europe and the United States themselves),

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<sup>46</sup> Interview with Julio Frenk, October 2010.

<sup>47</sup> Carlos Pucheu said this about the younger generation of Mexican psychiatrists in training. Alarcón, *Identidad De La Psiquiatría Latinoamericana : Voces Y Exploraciones En Torno a Una Ciencia Solidaria*, 1.th ed. (México, D.F.: Siglo Veintiuno Editores, 1990), 670 p.

<sup>48</sup> Some well-known antipsychiatrists, including Basaglia, fiercely rejected the label. The term was first coined by UK psychiatrist David Cooper in 1968 and came to be applied more widely. For more on UK antipsychiatrists David Cooper and R. D. Laing, see Zbigniew Kotowicz 1950-, *R.D. Laing and the Paths of Anti-Psychiatry* (London ;New York: Routledge, 1997), 132 p.

they held shifting ideas about psychiatry. This set of authors emerged in the late 1960s and challenged the dominant psychiatric orthodoxy of the mid-twentieth century. Some of the leading “anti-psychiatrists” who would influence the Mexican medical students included R.D. Laing in the United Kingdom and Franco Basaglia in Italy as well as the writings of philosopher Michel Foucault in France. Although their critics often dismissed them as radical nihilists hell bent on destroying care for the mentally ill, in fact these authors differed in how strongly they rejected outright mainstream psychiatric theory, how they viewed the concept of mental illness and their nations’ system of asylums or hospitals that had been the dominant way to treat the severely mentally ill in the twentieth century and earlier.

The antipsychiatric authors did not just criticize the abusive treatment of mentally ill in the asylums, though they certainly did so. Thomas Szasz in the United States, for example, attacked the very foundations of psychiatry as a discipline. When Szasz first published *The Myth of Mental Illness* in 1961, it shocked its global readership by attacking not only the institutional system of care that had prevailed during the 1950s, but also by venturing the idea that mental illness did not exist except as a tool of social control. Later work by UK psychiatrists RD Laing and David Cooper employed more abstract philosophical approaches to question how psychiatry came to diagnose patients and what those diagnoses meant.

Yet other so-called antipsychiatrists, such as Italian psychiatrist Franco Basaglia, took a more political, pragmatic and less philosophical approach to the problem of psychiatry. Of all the antipsychiatrists, Basaglia and his approach to Italian mental health reform would prove to be the most highly influential to Frenk and the Mexican students. As a young psychiatrist, Basaglia

focused his activism on deinstitutionalizing the grossly neglected Italian asylums, activities that attracted worldwide attention, including in Mexico. As a follower of the Freudian-Marxist Gramsci, Basaglia emphasized that psychiatry's claims of scientific objectivity amounted to an "alibi" seeking to exert power over proletariat and other undesirable elements of society. Thus, psychiatric diagnosis and subsequent institutionalization were anything but the natural, biological processes that the older generation of psychiatrists had claimed. For Basaglia, like Szasz, psychiatry was a state-controlled weapon of social control. He advocated for the closure of the asylums and their replacement with community and patient-run facilities without locked doors. Non-ideological and non-Eurocentric by disposition, he shrugged off attempts by his admirers to label his methods as the "Basaglian" school of thought.

As the older generation had done, the group of Mexican medical students looked to the ideas of these theorists for guidance in how to approach the problems with the psychiatric system within Mexico. In part, drawing on these authors reflected the lack of a homegrown antipsychiatric tradition in Mexico. However, the international cross pollination of antipsychiatric thinking reflected the general way that these concepts were flowing among countries. Reformers watched and learned from the experiences in other countries. For example, the passage of U.S. President John F. Kennedy's Community Mental Health Act (CMHA) in 1963 had been an early motivator to would-be reformers in other countries. Basaglia's fledgling views about the problems with the Italian asylums grew stronger by following the implementation of the CMHA in the United

States.<sup>49</sup> His efforts in Italian psychiatric reform eventually resulted in a concrete victory: the 1978 deinstitutionalization of all Italian mental asylums.<sup>50</sup>

As a result of these victories over the Italian psychiatric establishment, Basaglia became a hero to the Mexican psychiatric reformers. In 1978, the small group of Mexican antipsychiatrists invited him to speak at the First Conference on “Alternatives to Psychiatry,” held in Cuernavaca, Mexico.<sup>51</sup> While there, he argued that he had not come to teach specific lessons on psychiatric reform to Mexico, or any other country.<sup>52</sup> This anti-imperialist and open spirit endeared Basaglia to the Mexicans, both as a theorist and as an individual. Galvanized by Basaglia’s message, Julio Frenk drew on his writings more than any other critic of contemporary psychiatry. He even went

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<sup>49</sup> Michael Donnelly, *The Politics of Mental Health in Italy* (London ; New York: Tavistock/Routledge, 1992), 151.

<sup>50</sup> Italy had long been a leader of the antipsychiatric movement. Although the final date of this legislative victory came late, it was the culmination of years of antipsychiatric activism. For Basaglia’s own account of the legislative victory enacting the 1978 law, see Basaglia, Scheper-Hughes, and Lovell, *Psychiatry Inside Out*. For a secondary perspective, see Benjamin M. Meier, “The Highest Attainable Standard: The World Health Organization, Global Health Governance, and the Contentious Politics of Human Rights,” PhD diss.: Columbia University, 2009.

<sup>51</sup> Basaglia and Marcos, *Antipsiquiatría y Política*.

<sup>52</sup> Basaglia’s rationale for rejecting the phrase “Basaglianism” was that he rejected all ideology and asserted that every country needs to figure out its own approach to reforming its psychiatric system. See his interview with Sartre, collected in Basaglia, Scheper-Hughes and Lovell, *Psychiatry Inside Out : Selected Writings of Franco Basaglia* (New York: Columbia University Press, 1987a), xxviii, 318 p.

so far as to praise the Italian efforts to foster “antipsychiatric violence” for having “opened a gap in the monolithic structure of repressive psychiatry.”<sup>53</sup> It would be this passionate connection to antipsychiatric, and specifically Basaglian theory, as read and discussed in the cafes of Mexico City that would finally compel the students to set down their books and take action in the derelict asylums of the “farms.”

#### **1.1.4.. Battle in Print: The Medical Students’ 1977 Exposé of a Psychiatric Hospital**

The influence of the antipsychiatric movement on the Mexican medical students was not merely theoretical. After years of coursework, this same group of medical students went into their clinical rotations in *Las Granjas* with heads filled with the influences of the antipsychiatrists. The group of students who organized the self-taught seminar on social psychiatry theory would go on to put into practice some of the activist techniques of their heroes, the antipsychiatrists. Their desire to participate in the broader student, and specifically medical student, unrest during this period led them to engage in a bold act of exposure: the battle with their professors, the more traditional psychiatrists that has previously focused on curricular and pedagogical issues, now turned toward the care of the most ill patients.

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<sup>53</sup> It is not quite clear what violence Frenk was referring to, nor whether he was advocating violence as a tool to fight psychiatric repression. J. Frenk et al., "Instituciones Psiquiatricas Mexicanas: La Granja: Un Caso Desalador. (Mexican Psychiatric Institutions. La Granja: A Desolate Case). Report on the Conditions of a Mental Hospital." *La Cultura En Mexico, Suplemento De SIEMPRE!* 77, no. 5 (January 1977, 1977a).

In July 1977, Frenk and his fellow medical students served on a five-week psychiatric rotation at La Granja “La Salud Tlazolteotl,” one of the six rural “farm” hospitals that had been built after the 1968 destruction of La Castañeda asylum. Like other observers, the students found themselves utterly appalled by the conditions at this facility founded nine years earlier as an improvement on the old general asylum. As a result, they decided to plan an exposé of the asylum. During their five-week rotation at the La Granja, they snuck cameras into the hospital to document the conditions. After over a month of surreptitiously documenting the awful conditions they witnessed during their shifts, the group published a scathing exposé complete with photographs in *Siempre* magazine, a weekly cultural supplement read by socially progressive elites.<sup>54</sup> On a page with close-up photographs documenting toothless smiling faces of the patients, the student authors painted a bleak picture of the scene upon entering the facility:

A giant mass of human beings wandered aimlessly through a large passage. Many of them are shoeless, dressed in rags, covered in dust. They seem to have been there forever. Dirty faces, empty, fatigued by long years of confinement, crown their miserable bodies and oblivious to their current situation.<sup>55</sup>

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<sup>54</sup> To contextualize the elite standing of the magazine in Mexican society, in an interview, Frenk compared *Siempre* in Mexican society of the 1970s as similar to the *New York Review of Books* today. Interview with Julio Frenk, October 2011.

<sup>55</sup> J. Frenk et al., "Instituciones Psiquiátricas Mexicanas: La Granja: Un Caso Desolador. (Mexican Psychiatric Institutions. La Granja: A Desolate Case). Report on the Conditions of a Mental Hospital." *La Cultura En Mexico, Suplemento De SIEMPRE!* 77, no. 5 (January 1977, 1977a).

As the article proceeds, the anecdotes mount in their Kafkaesque absurdities: The sole medical resident in this male-only asylum is a gynecologist; new buildings that had been constructed to provide better conditions for patients stood empty and wasted because furniture had never been ordered, out in the field the cows kept to provide milk to feed the patients were unable to do so because they had fallen ill with dysentery that went untreated.<sup>56</sup>

In addition to documenting the general horror at the sanitary conditions and lack of treatment, the explicit influence of antipsychiatry pervades the essay. In keeping with the political orientation of the antipsychiatric movement, the role of the psychiatrist in the asylum was portrayed in stark terms of power and control. “The doctors here represent a piece of repressive machinery that acts in defense of the established order,” the students wrote. “In spite of their pretensions, the doctors’ role here does not situate them alongside scientists, but rather jailers, judges, police and soldiers.” Worst of all, they wrote, was the wing of the hospital known as “Pavilion G,” where the doctors did not even attempt to provide any ideological cover for their activities. Rather, the students decried, Pavilion G “is purely and openly a site of torture.”<sup>57</sup>

Mexico’s inertia toward improving the conditions of the mentally ill, the students charged, had condemned patients to living in this hellish status quo forever. Criticizing “the immutability of the asylum,” they denounced the fact that the original laws that had established Mexican asylums had not changed since their passage in 1838. These unchanging nineteenth-century features

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<sup>56</sup> Ibid.

<sup>57</sup> Ibid.

included “isolation in the extreme, strictly hierarchical organization, almost exclusive employment of medications as treatments and disregard for all types of psychotherapy.” The unhappy result was that life in the asylum existed in a “dimension where time has been fossilized by routine.”<sup>58</sup> Nothing and nobody changed.

Just as in previous decades their professors had worried about the “backward” state of Latin American psychiatry compared with that of the “advanced societies,” now these students wrote in their essays that Mexico should emulate those European countries and the United States that had sought to “liberalize and humanize the asylum.” By contrast, they complained, Mexico remained mired in the past, and the asylums presented, “at a distance of more than a hundred years, a faithful portrait of nineteenth-century principles.”<sup>59</sup> In fact, the situation could more easily be compared to the pre-nineteenth-century incarceration model, where the mentally ill were essentially jailed, than to rise of moral and therapeutic treatments in the late nineteenth century.<sup>60</sup>

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<sup>58</sup> Ibid.

<sup>59</sup> As will be discussed in the final section, almost the same criticism would be leveled against Mexican psychiatric facilities in 2004, after the WHO investigated the system that Frenk, then the Minister of Health, had requested. The WHO reviewers compared certain Mexican asylums to the infamous Benthamite “panopticon.” Organizacion Panamericana de la Salud, *Evaluacion De Servicios De Salud Mental En La Republica Mexicana* (Mexico, D.F.: Organizacion Panamericana de la Salud,[2004]).

<sup>60</sup> For more on the concept of the “moral cure,” see, among many other sources, Roy Porter 1946-2002. and David Wright 1965-, *The Confinement of the Insane : International*



### **1.1.5. Dr. Velasco vs. the Students: The Psychiatric Establishment Responds to the Exposé**

The students' exposé of the Granja hospital came out in the culturally elite *Siempre* magazine in January 1977. Prior to publication, the authors had feared either that they might be expelled for writing such a critique, or that no one in the public would care about it. Neither of those fears materialized; however, the article did cause an uproar at the highest levels of the Mexican psychiatric establishment. The following issue of *Siempre* ran a scathing two-page condemnation of the students' article, written by psychiatrist Dr. Rafael Velasco, professor at UNAM and former Director of Mental Health in the Secretary of Health.<sup>61</sup> Reflecting on the high-level response generated by their article, in 2010 Frenk interpreted Dr. Velasco's decision to respond to the article as a sign of the "double elitism" of Mexican society. As Frenk mused, the fact that one of the top leaders in psychiatry had to take this article seriously enough to respond reflected both the cultural impact of this magazine held among elites and the high social status that these student authors themselves held by virtue of the fact that they were being trained as future doctors.<sup>62</sup>

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*Perspectives, 1800-1965* (Cambridge, U.K. ;New York: Cambridge University Press, 2003), xvii, 371 p.

<sup>61</sup> Rafael Fernandez Velasco, "La Cultura, La Psiquiatra, Los Psiquiatras," *SIEMPRE!* 1231 (January 26, 1977, 1977), 56.

<sup>62</sup> Interview with Julio Frenk, October 2010. Basaglia had written about the oft-ignored social class issues that arose when elite medical students aligned themselves with patients from lower

In his response, Dr. Velasco did not contain his outrage at the students' impudence. "Owing to their incompetence," he wrote, "the student authors commit errors which could leave the reader with an incorrect idea about psychiatry and its true function." He wasted no time in pinpointing the theoretical source of the students' ideas: antipsychiatry. "There is clearly an echo of the words of the antipsychiatrists [here]" he wrote, and for them:

[m]ental illness does not exist except as a mere invention of society, a trap as intervention that the psychiatrist uses to imprison or brutalize with drugs those who step outside the patterns arbitrarily established by those who hold the power.<sup>63</sup>

Rejecting this caricature of psychiatry, Velasco reasserted his authority by reasserting his position as a man of science, and therefore rationality and objectivity. After dismissing the antipsychiatric movement as a political doctrine, rather than a science, he went on to declare that "it is through science that it can be refuted."<sup>64</sup> Here the scientific method itself threatens to unmask the antipsychiatrists as the political activists he believed them to be.

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classes. In such cases, despite their feelings of solidarity with the patients, the medical students often did not recognize their permanent privilege as members of a higher class and the tension this created. Here, Basaglia's intellectual debt to Antonio Gramsci becomes clear. For more, see Franco Basaglia, Nancy Scheper-Hughes and Anne Lovell, *Psychiatry Inside Out : Selected Writings of Franco Basaglia* (New York: Columbia University Press, 1987b), xxviii, 318 p.

<sup>63</sup> Velasco, *La Cultura, La Psiquiatra, Los Psiquiatras*, Vol. 1231, 1977), 56.

<sup>64</sup> Ibid.

Closing this initial letter to the editor, Velasco rejected out of hand the charges of oppression and malevolence that the students had leveled against psychiatry. Psychiatry, he wrote, “is not an oppressive agent of entrenched power nor is it interested in causing anyone suffering.” He accused the future doctors of the same intolerance they had charged the establishment with, ending his piece on a scolding note:

It would be better if those who aspire to be doctors would inform themselves first about that which they are going to criticize, and above all, to listen without prejudice (all prejudice is unscientific) to what those who hold different points of view say.<sup>65</sup>

The students did indeed listen to Dr. Velasco’s words. In February 1977, less than a month after Dr. Velasco’s letter was published, they returned the volley with a new article written directly in reply. The title alone made clear that there would be no concessions: “The Dogmas of Dr. Velasco: Scientism, Ideology and Psychiatric Discourse.”<sup>66</sup> Velasco’s very letter, they wrote, “represents the best testimony about the deficiencies that characterize official psychiatry in Mexico.” Reflecting the antipsychiatric tendency to link psychiatry with religion, they wrote that

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<sup>65</sup> Ibid.

<sup>66</sup> Note that Velasco in the 1950s had railed against dogma and upheld reason. The repetitive nature of the successive generations of youthful psychiatrists’ complaints reflects the power of certain tropes as rhetorical devices. See Sánchez-Mejorada, *La Psiquiatría Mexicana En Deuda: Una Semblanza De Rafael Velasco Fernández*, Vol. Number 11, 2010).

Velasco's dogmatic tone served to "impose a kind of catechism of psychiatry" and demonstrated an "abysmal disdain for public opinion and the function of independent criticism."<sup>67</sup>

Further, they asserted that Dr. Velasco's ire stemmed from the public nature of their article: "It bothers Dr. Velasco that we have brought matters to public light that traditionally were settled in the closed shop of psychiatric bureaucracy."<sup>68</sup> They went on to dramatize their claims about the oppressive hierarchy in Mexican psychiatry by personalizing the issue. Rather than speaking directly to their professors about their concerns regarding *La Granja*, the Spanish term for these new "farm hospitals," they decided to publish the exposé in print because they feared academic retaliation. Referencing student-professor power differences, they complained that Velasco's letter sought to "undermine the validity of our criticisms by the simple fact that we are students. All this reflects more than any report the repressive and hierarchical character of Mexican psychiatric institutions."<sup>69</sup>

Science became the contested prize in this war of words. In his initial letter, Dr. Velasco had labeled the antipsychiatrists as "guerrillas." The students pounced on this diction. "It seems

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<sup>67</sup> Julio Frenk et al., "Cientificismo, Ideología Y Discurso Psiquiátrico: Los Dogmas De Doctor Velasco (Scientism, Ideology and Psychiatric Discourse: The Dogmas of Doctor Velasco)," *Suplemento De SIEMPRE*, no. 782 (February 18, 1977, 1977b).

<sup>68</sup> Ibid.

<sup>69</sup> Ibid. Julio Frenk et al., "Cientificismo, Ideología Y Discurso Psiquiátrico: Los Dogmas De Doctor Velasco (Scientism, Ideology and Psychiatric Discourse: The Dogmas of Doctor Velasco)," *Suplemento De SIEMPRE*, no. 782 (February 18, 1977, 1977b).

necessary to clarify to Dr. Velasco,” they cheekily noted, “that the word ‘guerrilla’ has a very precise meaning...until now there is no scientific evidence that Laing, Cooper or Basaglia ever used the tactic of armed warfare.” Such overblown rhetoric made sense, because those charged with “crushing” dissident movements often resort, as Velasco had, to distorting and manipulating language in order to “demonize” perceived dissident movements. In this way, the psychiatrists were no better than other censors of government.

The students’ essay cited various antipsychiatric theorists, both with and without attribution. However, it was Italian antipsychiatrist Franco Basaglia who emerged in this piece as their foremost theoretical inspiration.<sup>70</sup> They rejected Velasco’s assertion that all antipsychiatrists deny the reality of mental illness. Not so, the students wrote: Basaglia attacked not the concept of mental illness itself, but rather the “ideology” which “seeks to smother all contradiction.”<sup>71</sup>

#### **1.1.6. Science vs. Scientism: “We Are Advocates, Not Activists”**

In the interchange between Velasco on the one side, and Frenk and his fellow students on the other, both asserted that they themselves embraced science while the other expressed nothing but dogma. Velasco had accused them of ideology; they accused him of dogma. Both accused the

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<sup>70</sup> For example, without attribution, they quoted Foucault’s *Madness and Civilization* to declare that psychiatry had become nothing but a “monologue of reason about madness.”

<sup>71</sup> Julio Frenk et al., “Cientificismo, Ideología Y Discurso Psiquiátrico: Los Dogmas De Doctor Velasco (Scientism, Ideology and Psychiatric Discourse: The Dogmas of Doctor Velasco),” *Suplemento De SIEMPRE*, no. 782 (February 18, 1977, 1977b).

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other of not being “scientific.” For example, they had accused psychiatry’s efforts to force the field into narrowly biological reductionist categories of having achieved, they scorned, not science but “scientism.”<sup>72</sup>

In rejection of this charge, alongside their fervent endorsement of antipsychiatric theory and language, the students also took steps in their article to carefully maintain their social authority as scholars of science. The students mixed their ideological and political attacks with claims that focused on matters of policy or scientific evidence. For example, in both the original exposé and the response, they delivered a sternly worded critique of the Granja’s use of electroshock, insulin therapy and other invasive treatments. Rather than asserting the barbarity of such practices, as other activists did, they objected as scientists would, by citing recent research that had demonstrated the dangers of electroconvulsive therapy. They noted that the WHO had recently declared this treatment to be “without scientific rational basis.”<sup>73</sup>

This conscious self-presentation as scientists did not only take the form of explicit arguments. In a 2010 interview, Frenk reviewed a print copy of the exposé. He pointed out a table on the second page of the original article. The inclusion of this table, he reasoned, had a greater symbolism and strategic purpose:

We [the medical students] were trying to take photographs and we did a documentary, but then [laughing] you see that we then include a table in the middle of the article. We were trying to say we are *advocates*, but we are not *activists*. We

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<sup>72</sup> Ibid.

<sup>73</sup> Ibid.

are aspiring doctors and we are denouncing something that is very bad, but we are trying to do that armed with *evidence*.<sup>74</sup>

The 2010 distinction that Frenk later drew between activism and advocacy shows how carefully he and his colleagues honed their rhetoric to distance themselves from pure activism. The social status that they gained as students of science helped to bolster the political credibility of their more activist-like statements. This early care to strengthen moral impulses with legitimating forms of knowledge, such as quantitative metrics, would characterize much of Frenk's career in later decades.

When this essay drew the attention of journalists, the subsequent interviews gave the students another chance to provide their own sociopolitical condemnation of the Mexican psychiatric system.<sup>75</sup> One such group interview with the student authors drew out their views on the causes of the abuses witnessed at the farm asylum and made clear the centrality of the sociopolitical interpretations of those wrongs. One of the student coauthors, Mauricio Ortiz, expressed a Basaglian perspective when he pointed out that:

almost all the patients are proletariat or underclass. And in spite of the fact that madness is explained as a natural accident, disconnected from social determinants, curiously very few of the members of the rich class suffer from it.<sup>76</sup>

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<sup>74</sup> Interview with Julio Frenk, October 2011.

<sup>75</sup> The reporter who wrote about the students' exposé used a strong headline, "Mentally Ill Where There Used to Be Chickens," to capture the horror of the part of the asylum the students had identified as the worst of the ones they had visited. Federico Campbell, "Pabellon 'G': Enfermos Mentales Donde Habian Gallinas (Pavilion 'G': Mentally Ill Where there used to be Chickens)," *Proceso*, July 25, 1977, 1977, 18.

<sup>76</sup> Ibid.

In the Mexican economic context, Ortiz bitterly noted, the asylum directors' indifference to rehabilitation made some perverted sense. "What sense is there," he asked, "in rehabilitating a group of proletariats in a country where 40% of the economically active population is unemployed or underemployed?"<sup>77</sup>

The non-democratic nature of the psychiatric establishment drew further student criticism. The oligarchy of psychiatrists in charge of the country's system infuriated the students, who subscribed to Basaglia's vision of a "democratic psychiatry," one open to influence from outside the closed circle of psychiatrists.<sup>78</sup> In print and in person, Frenk attacked his professor and leading psychiatrist Ramón de la Fuente for running Mexican psychiatry much like a "cacique"—an old party boss—would run a political machine.<sup>79</sup>

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<sup>77</sup> Ibid.

<sup>78</sup> Basaglia, Scheper-Hughes and Lovell, *Psychiatry Inside Out : Selected Writings of Franco Basaglia* (New York: Columbia University Press, 1987b), xxviii, 318 p.

<sup>79</sup> Interview with Julio Frenk, July 2010. In fact, as a medical student, Frenk had been so bold as to attack the dynastic and closed nature of Mexican psychiatry, even in its own journals. In August 1977, a new Mexican psychiatric journal, *Salud Mental*, or *Mental Health*, published its first issue. Frenk wrote a review of the whole issue, complaining that the journal was written from "the point of view of the dominant psychiatry ideology in Mexico." He sarcastically noted that the main background article had been written by Dr. Ramon de la Fuente, who, he noted, at once held positions of Director General of Mental Health at the Secretary of Health, Director General of the Mexican Center for Studies in Pharmacodependency, etc.



In her interview with the reporter, the sole female co-author of the exposé, Aurora Orzechowski, diagnosed the social blindness that corroded psychiatry in Mexico:

None of the psychiatric authorities study the society and the families from which the patients come. The social component is very important but the psychiatrists who have the medical power in Mexico see everything from a very biological perspective, as if the social was not a palpable thing. By not seeing the social causes, they cannot avoid or prevent mental illnesses.<sup>80</sup>

As middle-class representatives themselves, the student activists' championing of these somewhat radical ideas reflected and reinforced general curiosity and concern among the educated, elite class of Mexicans at the time. In recognition of this interest, in 1977 the weekly cultural magazine *Cultura en México* decided to provide its readers with a "brief anthology of antipsychiatric thought," devoting three full pages to writings of both antipsychiatrists and defenders of traditional psychiatry, including Basaglia, Velasco, Laing, Foucault and Szasz. For readers interested in learning more, the piece ended with an extensive bibliography of further antipsychiatric readings available in Spanish.<sup>81</sup>

In addition to decrying the sociopolitical harms of the asylum, Frenk and his colleagues also emphasized the classic trope of asylum as prison, and institutionalization as imprisonment. Frenk echoed this traditional rhetoric during a roundtable discussion in February 1977 (a few months after the publication of their exposé). The event, hosted by UNAM's School of Law

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<sup>80</sup> Campbell, "Pabellón 'G.'"

<sup>81</sup> Editorial Board., "La Moda Y Los Avestruces: La Antipsiquiatria, Una Realidad Soslayada (Fashion and the Ostriches: Antipsychiatry, a Hidden Reality)," ?? (1977).

(notably, not the medical school), framed both prisons and asylums as “institutions of marginalization.”<sup>82</sup> In his remarks that day, Frenk expressed the classic antipsychiatric metaphor that psychiatrists were jailers, since both were “professionals of segregation” presiding over “spaces of marginalization.” Just as Basaglia had connected asylums and prison, Frenk wrote that both the “prison and the asylum participated in similar pernicious processes of social control,” from the “myth of penitentiary correction to the fiction of medical treatment, from penal punishment to therapeutic repression.” Among other faults, he noted Mexican psychiatry’s “medicalization of madness in the extreme...and the issue of consolidating a monolithic power.”<sup>83</sup>

The social power of psychiatry, Frenk suggested, came from its ability to institutionalize vast numbers of the population. Bemoaning the lack of Mexico-specific data, he cited statistics from the United Kingdom and United States to show the high percentages of those who would be hospitalized in their lifetime.<sup>84</sup> Referencing Basaglia, he observed there must be a problem with a diagnostic system in which the majority of people appear to have some form of mental illness. The power of the few to institutionalize the many created the immoral situation of “the

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<sup>82</sup> Julio Frenk, "El Manicomio, Institucion Carcelaria," *La Cultura En Mexico, Suplemento De SIEMPRE!* No. 795 (May 20, 1977, 1977), V.

<sup>83</sup> Ibid.

<sup>84</sup> Ibid.

marginalized majority.”<sup>85</sup> To Frenk, psychiatry seemed to be willfully blind to the relationship between social and economic problems and mental illness. As Frenk wrote, “psychiatrists seek to reduce a phenomenon which is a product of socioeconomic and cultural conditions to a situation that is strictly medical.”<sup>86</sup> At a time when the so-called biomedical model of psychiatry was gaining traction (as will be discussed in Section II), Frenk staunchly situated himself as a critic of this new reductionism.

#### **1.1.7. Civil Society: Virginia Gonzalez Torres Takes on the Psychiatrists**

In addition to the conflicted dyad of the psychiatrists and the medical students, others worked at the psychiatric facilities and voiced their own critiques of the system. In addition to other health care workers, such as nurses and social workers, a group of “lady volunteers” began to work at La Castañeda, and later the smaller offshoot facilities. In his reflections on his tenure as chief of La Castañeda, Guillermo Calderón described how this volunteer program began with his own wife, Maria Pilar, who began to accompany him to the asylum and to interact with the female patients.<sup>87</sup> This program stands out because during the 70 years of single-party rule in Mexico, the government had ensured that civil society remain weak.<sup>88</sup> Soon, the couple had enlisted the

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<sup>85</sup> Ibid.

<sup>86</sup> Ibid.

<sup>87</sup> Calderón Narváez, *Las Enfermedades Mentales En México : Desde Los Mexicanos Hasta El Final Del Milenio*, 1a, mayo 2002 ed. (México, D.F.: Editorial Trillas, 2002), 164 p.

<sup>88</sup> Lakin, “The Possibilities and Limitations of Insurgent Technocratic Reform.”

aid of their elite circle of friends and families. High-society ladies, often in defiance of their families' wishes, began to devote their time to visiting the mentally ill living in the appalling conditions of the asylum. Following the hierarchical nature of the system, most of these female volunteers, like the female nurses, followed the psychiatrists' orders.

One of these “lady volunteers,” however, did not stay silent. Born into a wealthy and prominent family in 1950s Mexico City, Virginia Gonzalez Torres seemed destined to live the life of quiet privilege typical of a woman of her socioeconomic position. While her three brothers all became highly prominent in their own fields, it would be her sister, Margarita, who was to change the course of her life.<sup>89</sup> Virginia became radicalized to the treatment of the mentally ill in 1973, in her early 20s. In 1973, her sister Margarita was flying home from a holiday when she became gravely ill on the flight from Paris to New York City. During the flight, she became agitated and began to make a scene. By the time the plane touched down in New York City, the authorities seized her and, rather than allowing her to board the connecting flight that would take her home to Mexico, they committed Margarita to the locked psychiatric ward of Bellevue

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<sup>89</sup> Victor Gonzalez Torres opened Farmacias Similares, a highly successful national chain of generic pharmacies in 1997; Jorge is the founder of the Green Party (Partido Verde Ecologista de México). Her third brother, Enrique, is a Jesuit priest who eventually became a university president. For more on her family, see Jaime Aviles, *Los Manicomios Del Poder: Corrupcion Y Violencia Psiquiatrica Den Mexico* [Asylums of Power: Corruption and Psychiatric Violence in Mexico] (Mexico City: Random House Mondadori, 2007), 230.

Mental Hospital in New York. (Later, she would be diagnosed with manic depression, now called bipolar disorder.)<sup>90</sup>

The task of retrieving Margarita from Bellevue fell to her sister Virginia, then in her early 20s.

Virginia flew to New York to collect her from Bellevue and bring her back to Mexico.

Stepping on the psychiatric ward opened Virginia's eyes to a problem she had never known about. She found herself appalled at what she saw and heard and smelled. In an echo of the narratives told by the psychiatrists about encountering the conditions at La Castañeda for the first time, Virginia described a tale of horror in which patients were living in their own urine and feces. Her vivid description of the sights and sounds of the asylum serve to reinforce the moral urgency of a situation otherwise hidden from view.

This experience galvanized Virginia and made her dedicate her life to helping the mentally ill of Mexico. Upon returning home with her sister, Virginia began to visit the patients in the mental hospitals outside Mexico City. There, she sat with the patients and spoke to them in an attempt to bridge divides of language and cognition to learn more about life in such a facility. As had occurred with Julio Frenk and the elite medical students, over time, the class differences between Gonzalez Torres and the patients diminished in her own view. Despite her wealth and social standing, in her mind she shared their sense of relative powerlessness before the establishment: in the rigidly hierarchical world of psychiatry, she was a young woman, with no advanced degree, let alone a medical degree. "I didn't have any formal training," she recalled. "I was an autodidact, but I felt an alliance with the patients; I didn't relate to the white

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<sup>90</sup> Interview with Virginia Gonzalez Torres, July 2010.

coats, I related to the patients.”<sup>91</sup> Despite her clear role as an elite member of Mexican society, this proud outsider status would long remain central to her public persona.

In a 2010 television interview, echoing the statements of the psychiatrists and medical students, she remembered the conditions she saw in the early 1970s. “When I started working in this field, there was no hope. Daily torture, hopelessness. The doctors couldn’t do anything to help the patients—no mattresses, food, clothes, shoes.” In fact, the asylum “was like a cuckoo’s nest,” she recalled in 2010, referencing the blockbuster film, “One Flew over the Cuckoo’s Nest.”<sup>92</sup>

Her critiques of the psychiatric system echoed those of the medical students as well as the antipsychiatrists. She drew similar analogies to war zones and criminal acts: “One time, I invited a war correspondent to visit the asylums, and he had to go out on the patio and cry because the conditions were so bad.” She drew attention to the similarity between asylums and jails: “Such stupid psychiatry! This is how we lived in Mexico: psychiatrist pigs who didn’t understand their profession, thought that they were jailers.” Like Basaglia, she noted that not only was confinement in the asylum non-therapeutic, it actually led to iatrogenic (medically induced) harms. As she recalled, “The crimes committed there! Many people didn’t enter in

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<sup>91</sup> Ibid.

<sup>92</sup> The film “One Flew Over the Cuckoo’s Nest” was released in 1975 and was based on the 1962 novel of the same name. Ken Kesey, *One Flew Over the Cuckoo’s Nest*, 40th anniversary ed. (New York: Viking, 2002), xxiv, 281 p.

such bad condition, but they got worse. The system harmed you.”<sup>93</sup> Specifically, she recalled one woman who was locked in an isolation room for five years and, upon release, quickly killed herself.”<sup>94</sup>

In response to what she viewed as horrific torture, Gonzalez Torres began to organize and set up a volunteer program to visit patients in what she called one of the “worst places,” Sayago Hospital.<sup>95</sup> Like Frenk, in her own way Gonzalez Torres reveled in her role as a gadfly to the psychiatric establishment, who, as she later noted with some pleasure, loathed her new initiative to bring in more volunteers to interact with patients and improve services. “[The psychiatrists’] resistance was total,” she claimed.<sup>96</sup> She went on to claim that Dr. Jesus Kumate,

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<sup>93</sup> Interview with Virginia Gonzalez Torres, July 2010. Note that her referral to psychiatric practice as “crimes” and psychiatrists as “criminal” echoes the antipsychiatric rhetoric. Franco Basaglia had contributed to a volume called *Peacetime Crimes*. The volume’s title derived from his experiences as a psychiatric intern post-WWII, when Basaglia first experienced the sensory overload of an Italian state-run mental hospital—odor, defecation, filth. The experience viscerally reminded him of his wartime experience of German concentration camps in WWII. This feeling of *déjà vu* led him to equate the peacetime actions in mental hospitals with wartime crimes. Basaglia, Scheper-Hughes and Lovell, *Psychiatry Inside Out : Selected Writings of Franco Basaglia* (New York: Columbia University Press, 1987b), xxviii, 318 p.

<sup>94</sup> Interview with Virginia Gonzalez Torres, July 2010.

<sup>95</sup> Later, in November 1980, Gonzalez Torres founded the Mexican Foundation for Psychosocial Rehabilitation (FREM, *Fundación Mexicana para la Rehabilitación del Enfermo Mental*), which continues to operate today.

<sup>96</sup> Interview with Virginia Gonzalez Torres, July 2010.

the Japanese-Mexican, then Secretary of Health, had declared that “psychiatric patients don’t have human rights in Mexico.”<sup>97</sup>

Despite her use of similar language as the antipsychiatrists to denounce the psychiatric establishment, Gonzalez Torres was not interested in theory and did not explicitly ground her approach in any theoretical understandings of mental illness. Nevertheless, her writings and speeches do implicitly reflect the metaphors and imagery of the antipsychiatrists. Her most explicit influence was that of international social justice movements, such as resistance to Nazism and the US civil rights movement. Hailing her own activist movement as the “Psychiatric Revolution,” her speeches consistently compare her own efforts to those of Martin Luther King and Mahatma Gandhi. Indeed, such dramatic accounts have been an integral part of her advocacy, just as publishing the exposé had served a similar purpose for the medical students. In a country where both press and civil society were suppressed by government, she declared that through her alliance with both, “together we launched a revolution.”<sup>98</sup>

In contradiction to the antagonistic persona and activist stance she cultivated during those years, Gonzalez Torres did not criticize or reject the fundamental conceptual foundations of psychiatry nor its diagnostic categories. Instead, like Frenk, with whom she later worked in the Ministry of Health, hers was a more pragmatic goal: to strengthen patients’ rights to receive

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<sup>97</sup> Ibid.

<sup>98</sup> Ibid.



care and rehabilitation.<sup>99</sup> When asked by a television reporter what she wanted for the patients, she replied, “just care.”<sup>100</sup>

By the end of the 1970s, Frenk’s career moved away from psychiatry and overt activism. After graduating with his medical degree in 1979 from the National Autonomous University of Mexico, Frenk moved to the United States to begin graduate school. Despite wishing to become a psychiatrist during medical school, he moved away from mental health and toward broader academic approaches. As he considered a postgraduate program, he decided to choose a public health program at the University of Michigan. After earning a master’s degree in public health, he earned a second master’s in sociology. In 1983, he earned a PhD in Medical Care Organization and Sociology, a field more suited to his population-level interests.

This choice to move away from psychiatry and toward public health and medical sociology was consistent with the critiques Frenk and his colleagues made during their stint as crusaders against the psychiatric system. Notably, while all the medical students involved in the self-run seminar on psychiatry and society and later the 1977 Granja exposé graduated and became physicians, none of them actually entered psychiatry. Most went into public health, which better allowed them to retain their commitment to social aspects of medicine. Speculating on this surprising uniformity of their career choices, Frenk reasoned that after the experiences that

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<sup>99</sup> Ibid.

<sup>100</sup> Note the perhaps unintended double entendre in the phrase “just care,” connoting both justice and effective treatment. Interview with Virginia Gonzalez Torres, July 2010.

they underwent, he and his colleagues viewed psychiatry, at least as practiced in Mexico, as a discipline so hopelessly removed from their social and political perspectives and goals so as to render it unable to accommodate their expansive interests.<sup>101</sup>

Indeed, in Mexico, there continued to be a vast distance between psychiatry and socially oriented public health. Globally, the influence of the antipsychiatrists faded toward the end of the 1970s as the broader counterculture spirit of the 1960s began to dissipate. Franco Basaglia himself died prematurely in 1980, a further blow to the movement.

By the early 1980s, the previously dominant biologically oriented psychiatry was stronger than ever in Mexico, the neglect and isolation of patients in *Las Granjas* continued on as before, while outside the walls of the asylum, access to mental health care remained a privilege of elite Mexicans. Yet not all in the realm of Mexican mental health remained stagnant. The dawn of the 1980s saw the emergence of new forms of evidence and activism, ones that looked very different from the methods of the 1970s activists, but by which Frenk could adapt his initial goals to the new era. Rather than battles of words, the new debates over reform would focus on numerical issues, and arguments would be built on statistical and economic data more than through narratives of moral outrage built on photographic evidence and interviews.

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<sup>101</sup> Interview with Julio Frenk, October 2011.

## **PART 2**

### **“Mental Health Rises to the Top”:**

**Julio Frenk, Evidence-based Policy and the New Quantification of Mental Illness,**

**1983–2000**

#### **1.2. Introduction**

In 1980, Julio Frenk was a newly minted doctor pursuing a Master of Public Health degree at the University of Michigan. In 2000, he was appointed Mexico’s Minister of Health following the country’s first fully democratic election. Whereas Part I of this paper focused on his medical student activism in favor of psychiatric reform in Mexico, this section necessarily widens the analytic lens on his career. Across that 20-year span, Frenk became more of an establishment figure himself and made major contributions to the theory and practice of public health. In doing so, he moved away from a direct focus on mental health. As Frenk rose in prominence, Mexico itself underwent major political changes, such as the 1984 constitutional amendment that enshrined health as a human right, which opened the door for targeted health system reforms after 2000.<sup>102</sup>

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<sup>102</sup> Frenk co-authored a 1985 paper that discussed the health policy implications of the 1984 constitutional amendment. G. Soberon, J. Frenk and J. Sepulveda, "The Health Care Reform in Mexico: Before and After the 1985 Earthquakes," *American Journal of Public Health* 76, no. 6 (Jun, 1986), 673-680.

For a broader examination of how political changes in Mexico in the 1980s affected mental health policy, see Oliver G. Hernández Lara, “La metamorfosis de la política de salud mental en México,” master’s thesis, Instituto de Investigaciones José María Luis Mora, 2008.

This section examines Frenk's major efforts during these years and demonstrates that, despite the broadened scope of his initiatives, they contributed to a revolution in the perception of mental health as a problem of global public health. As will be shown in the next section, once Frenk became Minister of Health, the work he developed between 1983 and 2000 fueled his reengagement with more targeted efforts to reform the psychiatric system in Mexico.

Between 1983, when he moved back to Mexico after completing his PhD at the University of Michigan, Ann Arbor, and 1998, when he left Mexico for a cabinet position in the World Health Organization, Frenk pioneered new forms of public health research as he moved through a series of positions of increasing leadership and global visibility.<sup>103</sup> His graduate school training beyond medical school made this possible. Between 1981 and 1983, Frenk earned three advanced degrees: a Master of Public Health (1981), a second Master's in Sociology (1982), which he finally capped off with a joint PhD from the departments of Medical Care Organization and Sociology (1983). These additional years of training beyond medical school enabled Frenk, upon return to Mexico, to examine health and health systems from a more expansive and societal perspective than medicine alone could provide.

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<sup>103</sup> Some of Frenk's notable positions in between include: Founding Director of the Center for Public Health Research at the Ministry of Health (1984–1987), Founding Director General of the National Institute of Public Health (1987–1992), Director of the Project on “Health and the Economy” at the Mexican Health Foundation (1993–1995) and Executive Vice President and Director of the Mexican Health Foundation (1995–1998).

In addition, beginning in graduate school, Frenk began to rethink the very concepts of public health and to champion an ambitious, holistic vision for public health, one he later would dub the “New Public Health.”<sup>104</sup> As Frenk wrote in a 1986 conceptual article: “What distinguishes public health research from clinical or biomedical research is that those approaches work, respectively, on analyses at the individual or a sub-individual level,” whereas public health operates at a population level of analysis.<sup>105</sup> As an example, beginning in 1980, Frenk published several articles about the Mexican labor market for physicians and the problem of physician underemployment.<sup>106</sup>

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<sup>104</sup>A selection of these conceptual publications includes the following: E. Ruelas and J. Frenk, "Framework for the Analysis of Quality Assurance in Transition: The Case of Mexico," *Australian Clinical Review / Australian Medical Association [and] the Australian Council on Hospital Standards* 9, no. 1 (1989), 9-16.; Julio Frenk, "Social Origin, Professional Socialization, and Labor Market Dynamics: The Determinants of Career Preferences among Medical Interns in Mexico," *Perspectivas En Salud Pública* 4 (1988).; Frenk, *The New Public Health*, Vol. 14 Annual Reviews 4139 El Camino Way, PO Box 10139, Palo Alto, CA 94303-0139, USA, 1993a), 469-490.; Julio Frenk Mora et al., "Un Modelo Conceptual Para La Investigación En Salud Pública; A Conceptual Model for Public Health Research," *Bol.Oficina Sanit.Panam* 101, no. 5 (1986), 477-492.

<sup>105</sup> Julio Frenk Mora et al., "Un Modelo Conceptual Para La Investigación En Salud Pública; A Conceptual Model for Public Health Research," *Bol.Oficina Sanit.Panam* 101, no. 5 (1986), 477-492.

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<sup>106</sup> For instance, beginning while still at Michigan, Frenk began to publish extensively about the labor market for physicians in Mexico and the problem of medical underemployment. For a range of his publications in this area, see Julio Frenk, "Career Preferences Under Conditions of Medical Unemployment: The Case of Interns in Mexico," *Medical Care* (1985), 320-332.; Julio Frenk, *El Mercado De Trabajo Médico* División Ciencias Biológicas de la Salud, Núcleo de

Moving from an individual to a population level of analysis entailed an epistemological shift in what knowledge researchers valued and pursued, and therefore what data was generated.

Distancing himself from his medical student days of sneaky camera exposés and condemnation of the sociopolitical failures of the psychiatric system, Frenk now conducted statistically grounded, economic and system-level analyses. Numbers and empirical evidence replaced photographs and written polemics to describe the problems of public health. Yet, although this dramatic change from a rights-based to a quantification-based approach to public health seems like a complete rupture with his past, tracing Frenk's career in the 1980s and 1990s reveals considerable continuity with the moral impulse behind his earlier work in the asylums.

This section argues that, although Frenk did not research or publish on mental health during the 1980s, he engaged in developing what he called "evidence-based policy": that is, conceptual and methodological advances which reframed public health research in general, and specifically in terms of epidemiological and economic research. This body of work provided the intellectual foundation that made possible the Global Burden of Disease (GBD) study of the early 1990s, which itself represented a revolutionary game-changer in global mental health. The impact of the

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Investigación y Desarrollo en Educación y Salud, Universidad Autónoma Metropolitana, 1980).; J. Frenk, H. Hernandez Llamas and L. Alvarez Klein, "El Mercado De Trabajo Medico. II. Evolución Histórica En Mexico," *Gaceta Médica De México* 116 (1980), 265-284.; Julio Frenk, "The Political Economy of Medical Underemployment in Mexico: Corporatism, Economic Crisis and Reform," *Health Policy* 15, no. 2 (1990), 143-162.

1990 GBD study spawned initiatives to prioritize mental health in low-income countries. Frenk himself returned to mental health in 1998 when he joined the WHO cabinet, and used the tools developed in the 1990s to further push mental illness to a place of unprecedented visibility as a public health problem deserving priority on both the Mexican and global agendas. By the time Frenk returned to Mexico to assume the position of Minister of Health in 2000, mental health had never had such a high profile in global public health. Yet real change in the Mexican mental health would require more than visibility.

### **1.2.1. While Frenk Was Away: Mental Health in Mexico, 1979–1983**

When Frenk moved back to Mexico, after four years abroad, he returned to a landscape in which psychiatry and mental health policy had not much changed from the status quo he had attacked as an antipsychiatric activist cum medical student. In Mexico, as in other countries, the 1980s were a time of retrenchment of conservatism in psychiatry (as well as in politics in general). The global antipsychiatric movement, which had dominated psychiatric reform efforts in the 1970s, slowly began to dissipate.<sup>107</sup> Although Frenk himself did not focus on mental health in this decade, understanding the major issues in Mexican psychiatry helps clarify how his contributions

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<sup>107</sup> A few notable examples of antipsychiatric activities in Mexico remained. In 1981, the Alternatives to Psychiatry group (the same group that had held the first conference in Cuernavaca which Franco Basaglia attended in 1979) reconvened despite Basaglia's 1980 death. Encuentro Latinoamericano de Alternativas a la Psiquiatría and Sylvia Marcos, *Manicomios Y Prisiones : Aportaciones Críticas Del I Encuentro Latinoamericano Y V Internacional De Alternativas a La Psiquiatría, Realizado En La Ciudad De Cuernavaca Del 2 Al 6 De Octubre De 1981*, 1a. ed. (Mexico City, Mexico: Red Ediciones, 1983), 277 p.

For an account of how antipsychiatry evolved into a more consumerist movement, see David Rissmiller and Joshua Rissmiller, "Open Forum: Evolution of the Antipsychiatry Movement into Mental Health Consumerism," *Psychiatric Services* 57, no. 6 (2006). (It should be noted that the antipsychiatric group MindFreedom denounced this article.)

to public health would, by the early 1990s and beyond, greatly transform the debates around Mexican mental health.

No dismantling of the hierarchical structures of Mexican psychiatry had taken place between 1979 and 1983. Those in leadership positions remained the same, even if they had shuffled positions a bit. Even the psychiatric dynasties continued: the Minister of Health during the late 1990s was Juan Ramón de la Fuente, son of the famous psychiatrist Ramón de la Fuente.<sup>108</sup> As Frenk and the once would-be student reformers rose to professional roles in their own careers, their former professors and antagonists became colleagues and less aggressive tactics prevailed. Debates now took the form of published research articles rather than journalistic exposés.

Mexican psychiatry always had its own trajectory, but in the 1980s, the Mexican mental health system diverged more sharply from that of countries it had long begrudgingly followed for its research and reforms in mental illness. This was because Mexico never undertook a systematic process of deinstitutionalization—transitioning from hospitals and asylums to community-based services or just releasing patients without follow-up—as had countries such as Italy, the United Kingdom and the United States.<sup>109</sup> The worldwide crisis in psychiatric legitimacy in the 1970s

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<sup>108</sup> As one of Julio Frenk's frequent collaborators Octavio Gomez Dantes wryly noted in an interview, "the way to remember who is father and who is son is that the son has the initials J. R., as in junior." Interview with Octavio Gomez Dantes, July 2010.

<sup>109</sup> Because of its historical importance, histories of psychiatry in those countries confront the causes and consequences of deinstitutionalization, or to use Roy Porter's phrase, the end of the "Great Confinement" that had begun in the nineteenth century. For historical accounts of deinstitutionalization in Europe and the United States, see Peter Barham, *Closing the Asylum: The Mental Patient in Modern Society*, Ringwood, Australia: Penguin, 1992; Roy Porter and David Wright, *The Confinement of the Insane*; Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health*, Abingdon, U.K.: Routledge, 2005.



had never taken hold at the top of Mexican psychiatry practice. The continuation of the status quo in the 1980s reinforced the antipsychiatric movement's prior complaints about stagnation in the field.

In Mexico, although the most egregiously decrepit hospitals—most infamously, La Castañeda—had been closed, little changed but the architecture. In many cases, the patients were simply transferred to smaller facilities that still functioned like asylums.<sup>110</sup> (Over time, many of the new hospitals descended to such decrepitude that a new hospital was built and the patients were transferred again.) In contrast to the United States or Europe, the principal locus of psychiatry in Mexico remained the psychiatric hospital. Similarly, although globally the growing availability of effective psychopharmaceuticals did enable many formerly institutionalized individuals to resume life in the community, few contemporary Mexican accounts of the rise of psychopharmacology mention anything beyond basic and clinical research into medications.<sup>111</sup>

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<sup>110</sup> In his 2002 personal history of mental illnesses in Mexico, Calderón Narváez, who oversaw the closure of La Castañeda, described the process of transfer as one of hope and improved care. Calderón Narváez, *Programa De Salud Mental Comunitaria En Mexico*, 1973), 430-438.; Calderón Narváez, *Las Enfermedades Mentales En México : Desde Los Mexicanos Hasta El Final Del Milenio*, 1a, mayo 2002 ed. (México, D.F.: Editorial Trillas, 2002), 164 p.

<sup>111</sup> For a US-focused take on the rise of psychopharmaceuticals and its relationship with community mental health in the early 1980s, see Robert E. Drake et al., "The History of Community Mental Health Treatment and Rehabilitation for Persons with Severe Mental Illness," *Community Mental Health Journal* 39, no. 5 (2003), 427-440.

In Mexico, while the memoirs of psychiatrists who worked during the 1980s praised the new psychotropic medications, it is hard to assess whether this change actually impacted hospitalizations and release.

Thus, early 1980s debates in Mexican psychiatry rehashed many of the key issues of the 1970s. As before, many argued that Mexico still needed to develop a national psychiatry independent both in its theories and in its research. Both the former antipsychiatrists and psychiatrists agreed that Mexico should not look to Europe or the United States for either data or guidance on mental health system reform. Yet how the vision for this desired independence should manifest itself took on different forms between the two groups in this decade.

The establishment psychiatrists, like Frenk's former antagonist Ramón de la Fuente, worked on developing a rigorous research program in psychopharmacology and neurology as the best means to achieve a truly home-grown Mexican psychiatry. The explicit argument was that such a rigorous program of research would help overcome psychiatry's perceived illegitimacy as a branch of science.<sup>112</sup> In 1979, de la Fuente founded the National Institute of Psychiatry to increase the output of Mexican basic clinical research into the brain.<sup>113</sup>

For de la Fuente, this new institute represented a key step toward modernizing Mexican psychiatry and, in so doing, freeing it from the uncomfortable intellectual dependence on

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<sup>112</sup> De la Fuente Muñiz, Ramón, *Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría*, Vol. 92, 2006), 52-55.

<sup>113</sup> It has since been renamed the Ramón de la Fuente Institute of Psychiatry.

European or US research or theory.<sup>114</sup> Its impact on patient care went unremarked upon. In 1984, de la Fuente spoke at a roundtable commemorating 40 years of the National College of Medicine. In his remarks, he lauded the Ministry of Health for building 11 new hospitals between 1960 and 1970 to replace La Castañeda.<sup>115</sup> Dismissing the fact that the new facilities were “farther from medical centers and badly distributed across the country,” de la Fuente boasted that “without a doubt that represented a favorable change, mainly because they made it possible to conduct more research.”<sup>116</sup> The perpetuation of the hospital-based mental health system created a captive audience of patients that enabled Mexican psychiatric research to advance to a world-class level.

The biological focus had been a mainstay of Ramón de la Fuente’s approach, but Mexico experienced the same turn towards biomedical and psychopharmacological research in 1980s. His main source of praise was the trend away from psychoanalysis and toward the biomedical model. Looking back on his career in 2006, de la Fuente wrote:

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<sup>114</sup> de la Fuente Muñiz, Ramón, "Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría," *Letras Libres: Edición México* 92 (August, 2006, 2006), 52-55.

<sup>115</sup> Ramón de la Fuente and Colegio Nacional (Mexico), *La Evolución De La Medicina En México Durante Las Últimas Cuatro Décadas : Conmemoración Del Cuadragésimo Aniversario De La Fundación De El Colegio Nacional*, 1a ed. (México, D.F.: El Colegio Nacional, 1984), 293 p., folded leaves of plates.

<sup>116</sup> Ibid.

Thanks to advances in neurosciences, psychoanalysis no longer dominates psychiatry as it did between 1940 and 1960, and psychiatry no longer stands removed from its roots in biological and experimental medicine....Today, the principal objective of scientific investigation in psychiatry is in relating discoveries derived from neuroanatomic, functional, neurochemical and molecular approaches to establish new psychopathology that also contains the social angle.<sup>117</sup>

This ultra-scientific approach did not reject patients' experience as much as fail to see it. By contrast, antipsychiatrists and mental health activists continued to argue that Mexican psychiatry exerted unjust power over the nation's poor. In 1981, at the Alternatives to Psychiatry conference, physician Carlos Rodriguez Ajenjo critically divided Mexican psychiatry into a set of dualistic categories. One form of psychiatry existed for the asylum/hospital versus private practice, organicist versus psychodynamic; one psychiatry was for the rich and another psychiatry for the poor. Ajenjo recalled Basaglia's exhortation that it was necessary to decide what to do and where to do it. Mexico's psychiatric reform, Rodriguez insisted, would be nothing like that of Italy or any other country. It would be its own.<sup>118</sup>

### **1.2.3. How Much and How Bad? Psychiatric Diagnostic and Measurement**

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<sup>117</sup> de la Fuente Muñiz, Ramón, *Memorias De Un Psiquiatra: De La Castañeda Al Instituto Nacional De Psiquiatría*, Vol. 92, 2006), 52-55.

<sup>118</sup> Encuentro Latinoamericano de Alternativas a la Psiquiatría and Marcos, *Manicomios Y Prisiones : Aportaciones Críticas Del I Encuentro Latinoamericano Y V Internacional De Alternativas a La Psiquiatría, Realizado En La Ciudad De Cuernavaca Del 2 Al 6 De Octubre De 1981*, 1a. ed. (Mexico City, Mexico: Red Ediciones, 1983), 277 p.

Yet conducting more rigorous research in psychiatry required the standardization of metrics, such as diagnostic reliability and validity, so that researchers could be sure that the same diagnosis made by an array of physicians consistently referred to the same disorder.<sup>119</sup>

Uncertainty about psychiatric diagnosis enabled the fierce debates about the existence of mental illness that had erupted between mainstream psychiatry and the antipsychiatrists, as well as fomenting turf wars between rival theoretical orientations among psychiatrists themselves. Some psychiatrists, including de la Fuente, complained that psychiatry's retreat from science had exacerbated the field's marginalization from medicine.<sup>120</sup>

The diagnostic categories of US psychiatry also seemed to exclude Latin American reality. Some observers of Latin American psychiatry even went so far as to criticize DSM-style metrics for narrowly focusing on illness itself. In Latin America, the societal-level, non-health-related factors, such as the political and economic changes that swept the region during the 1980s, contributed a great deal to psychiatric problems. Itzak Levav, an Israeli psychiatrist who became the Regional Director of Mental Health for the Pan American Health Organization (PAHO), noted that violent behavior occurred in "outstanding" magnitude and severity in the region.<sup>121</sup> Although such violence led "to untold suffering and disability" as well as hampering economic

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<sup>119</sup> In the United States, where managed care organizations began to arise, standardizing diagnoses also aided the new managed care companies in billing.

<sup>120</sup> For more on the perception of marginalization among psychiatrists, see Part I.

<sup>121</sup> In 1991, Levav wrote the text of the Declaration of Caracas, a Latin America PAHO-led declaration in which countries committed to integrating mental health care into primary care and moving away from the asylum model.

growth, as long as no facts or figures could describe the impact of this violence, he complained, there would be and could be no public health response. The narrow diagnostic categories of psychiatry, Levav argued, failed to capture population-level social factors, such as urbanization, international displacement and high unemployment, leaving invisible such contributors to mental illness.

Nor did psychiatric epidemiology offer easy solutions to these problems of categorizing and measuring mental illness. Through the 1980s, epidemiological data at the national and international level focused on mortality by counting, aggregating and ranking the number of deaths due to various illnesses. However, mental illness causes a great deal of disability (morbidity) but relatively few deaths (low mortality). As long as the “badness” of disease was measured only in lives lost, mental illness would always languish as an issue of low importance epidemiologically, and therefore of low importance on the resource allocation agenda. Yet a metric for comparing morbidity across disease categories did not exist.<sup>122</sup>

In addition to epidemiology’s limited tools for psychiatry at that time, the lack of reliable diagnostic categories for psychiatric disorders made measuring numbers of diagnosed cases problematic. Through the 1970s, psychiatric nosology was based on theoretical, rather than descriptive, concepts of disorders. Depression, therefore, would be diagnosed differently,

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<sup>122</sup> That is not to say that future projections of prevalence and incidence of disease did not take place. For a 1989 example of such a projection of mental illness in Latin America, see Itzhak Levav et al, “Salud Mental para Todos en América Latina y el Caribe: Bases Epidemiológicas para la Acción” (Mental Health for All in Latin America and the Caribbean: Epidemiological Bases for Action), *Boletín de la Oficina Sanitaria Panamericana* 107, no. 3 (1989).

depending on whether a Freudian or a Jungian assessed the patient.<sup>123</sup> Without certainty that the same diagnoses reflected the same illnesses, no aggregate measures could be reliable. Finding a way to standardize psychiatric diagnosis offered the promise of better research, better patient care, and eventually greater social and professional legitimacy for psychiatry as a field.

In acknowledgment of these measurement problems, two initiatives to make psychiatric diagnoses more consistent between physicians and across nations arose. First, in 1975, the WHO issued its ninth revision of the International Classification of Diseases (ICD-9), which aimed to increase the reliability and precision of the standard diagnostic tools for many diseases. Although imperfect, the ICD-9 facilitated international comparisons within epidemiologic research. This international change was followed by the 1980 publication of the DSM-III, the third edition of the U.S.-based *Diagnostic and Statistical Manual for Psychiatric Disorders*.<sup>124</sup> Prepared in a series of heated negotiations between 1974 and 1979—years of great turmoil in psychiatry, this

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<sup>123</sup> These debates over epistemological and theoretical aspects of psychiatry are captured in Bayer and Spitzer's 1985 article detailing the contested process of creating the DSM-III. Since Spitzer was one of the leaders of these efforts, this article conveys particularly vivid, first-hand recounting of the turf wars. Ronald Bayer and Robert L. Spitzer, "Neurosis, Psychodynamics, and DSM-III: A History of the Controversy," *Archives of General Psychiatry* 42, no. 2 (1985), 187.

<sup>124</sup> M. Wilson, "DSM-III and the Transformation of American Psychiatry: A History," *The American Journal of Psychiatry* 150, no. 3 (Mar, 1993), 399-410.

For a more critical take on the DSM-III and the field of psychiatry, see Robert Whitaker, *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* (Basic Books, 2010).

new version of the manual aimed to recategorize mental illnesses away from the “biopsychosocial” model, which had dominated through the 1970s.<sup>125</sup> The DSM-III broke the previous standard by adopting an “atheoretical” descriptive nosology.<sup>126</sup> In other words, disorders would now be diagnosed by describing their symptoms rather their theoretical etiologies, as they had been so as to stave off turf wars between rival psychoanalytic schools.<sup>127</sup>

As a product of the American Psychiatric Association, the DSM-III would be disseminated globally with the imprimatur of American psychiatry. It thus stood in contrast to the ICD-9, which European psychiatrists favored. For Latin American psychiatry, this US stamp carried a mixed set of associations. In a 1983 piece titled the “Latin American perspective on the DSM-III,” published in a US journal, Peruvian psychiatrist Renato Alarcón predicted how Latin American psychiatrists would react to the new manual.<sup>128</sup> The “biopsychosocial” model of mental illness, which the DSM-III rejected, had been defended by the Mexican psychiatrists in the 1970s. Simply by virtue of being a product of American psychiatry, Alarcón wrote, the

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<sup>125</sup> Bayer and Spitzer, “Neurosis, Psychodynamics, and DSM-III.”

<sup>126</sup> Ibid.

<sup>127</sup> Ibid.

<sup>128</sup> Renato D. Alarcon, “A Latin American Perspective on DSM-III,” *Am J Psychiatry* 140 (1983), 102-105.



DSM-III would attract attention internationally. Its eventual fate, he wrote, would depend as much on general attitudes to American influence as on its merits.

On the negative side, Alarcón noted that the DSM-III lacked options for adaptation to various cultural contexts. Specifically, in an echo of Levav, Alarcón complained that the American notions of psychosocial problems could never match the reality of nations like those in Latin America, with their poverty, violence, etc. Yet over all, the reception of the DSM-III among Latin American psychiatrists would be warm, in large part because they had already been diagnosing based on symptoms long before the Americans decided to make this technique official.<sup>129</sup>

Despite some controversy surrounding the new manual, the adoption of internationally recognized definitions of mental illness created the necessary conditions to begin to conduct more refined international psychiatric epidemiology. The new standardization satisfied two wings of Mexican psychiatry: the old guard's impulse to make psychiatry into an objective science and the reformers' wish to prioritize mental illness.<sup>130</sup>

#### **1.2.4. Double Burden of Disease: Epidemiology and International Development, 1983–1993**

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<sup>129</sup> Ibid.

<sup>130</sup> In theory, the DSM-III would also reduce improper hospitalizations and abuses. Furthermore, in theory, patients would be more easily and reliably diagnosed by their visible symptoms and released if they did not meet the criteria for a DSM-III-recognized or hospitalization worthy diagnosis. Whether theory translated into practice in the Mexican psychiatric hospitals remains unclear.

When Frenk returned to Mexico in 1983, he immediately began to establish new avenues for public health research. That same year, he founded the Center for Public Health Research at the Ministry of Health. Frenk had joined the Health and the Economy project at the Mexican Health Foundation in 1985 and became its director in 1987. Frenk's public health research from 1980 on had examined the labor market and Mexican medical underemployment. Along with his previous economic research into the medical labor market in Mexico, this new position gave him legitimacy to speak out about the relationship between health and economics.

In the 1980s, an economic approach to health arose alongside the two former models that had been dominant throughout the 1970s: the sociopolitical and biomedical approaches to health. In the late 1970s, the World Bank expanded its scope beyond a narrow view of development to include formerly social factors such as health, nutrition and education.<sup>131</sup> In 1980, the Bank's annual World Development Report, entitled *Poverty and Human Development*, set the tone for the decade. This report represented the Bank's first attempt at reframing the realms of education, health and nutrition as instrumental inputs to the true goal of economic development. In poor countries, the report argued, premature mortality due to illness sapped workforce productivity and impaired development. In contrast to previous theories of development in which wealth would improve health, now the causal arrow pointed the other way: health would lead to wealth.

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<sup>131</sup> By contrast, the WHO rejected this economic perspective outright and argued that "health [should be viewed] as an instrument for development and not mere byproduct of economic progress." Marcos Cueto, "The Origins of Primary Health Care and Selective Primary Health Care," *American Journal of Public Health* 94, no. 11 (November 1, 2004), 1864-1874.

By improving health systems, poor countries could get on the path to more rapid development and, implicitly, to progress.

Epidemiological research—a core discipline of public health—provided a way to illuminate this new health-wealth relationship. In the 1980s, epidemiologic and economic inquiry grew more tightly intertwined than before.<sup>132</sup> More research began to investigate how changing epidemiological profiles—that is, the mix of types and patterns of disease in populations—affected nations’ economic development.

Broader efforts to theorize epidemiology and development had begun earlier. One of the most prominent such approaches had been Abdel Omran’s 1971 theory of the epidemiological transition.<sup>133</sup> The theory suggested that countries tend to proceed along linear stages of development, each characterized by a particular pattern of disease.<sup>134</sup> As countries grow more developed, the rates of diseases due to poverty—infectious diseases, malnutrition and poor sanitation—tend to decrease, while their rates of diseases of civilization—noncommunicable diseases, such as cardiovascular disease, diabetes and mental illness—would increase. Countries

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<sup>132</sup> World Bank. *World Development Report 1980: Poverty and Human Development*. Washington, D.C.: World Bank and Oxford University Press, 1980.

<sup>133</sup> Abdel R. Omran, “The Epidemiologic Transition: A Theory of the Epidemiology of Population Change,” *Milbank Memorial Fund Quarterly* 49, no. 4 (1971).

<sup>134</sup> *Ibid.*

fell into two categories: developed countries facing high levels of noncommunicable and chronic diseases and developing countries still struggling with infectious diseases and malnutrition.<sup>135</sup>

In the mid-1980s, Frenk began to develop a more nuanced take on the epidemiologic transition given the deficiencies of the influential linear model that Omran's first model described. The example of a country like Mexico—so modern in its cities yet mired in poverty in its rural areas—suggested that the progression may be more complicated than the previous model allowed. Frenk and colleagues began to use the improved epidemiologic instruments to examine the early work on the epidemiologic transition in Mexico.

In 1989, Frenk co-authored an article that made the case for transforming the understanding of the relationship between epidemiology and development. His three co-authors included his fellow rabble-rousers from his medical school days: Jose L. Bobadilla, Jaime Sepúlveda, and Malaquias Lopez-Cervantes.<sup>136</sup> This group of Mexican researchers assembled to draft an article that reconceived the relationship between epidemiology, government, and economic structures. In the paper, they argued that the conventional understanding of the march of epidemiological

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<sup>135</sup> Note that the World Bank's *World Development Report 1980* discussed within-country variation in life expectancy rates.

<sup>136</sup> Note that Bobadilla had been one of Frenk's coauthors on the 1977 exposé of La Granja that almost led to their expulsion from medical school. He later worked at the World Bank. In addition to reflecting the small size of the elite leadership in Mexican's health system, this connection highlights the personal and conceptual continuity between the early human rights focused advocacy and this later economic approach.

progress obscured important differences within countries, in particular, within middle-income countries.

Mexico, however, the authors argued, represented the “prototype” of a third category: the middle-income country faced with both the diseases of modernization and the “epidemiologic backlog.”<sup>137</sup> This was a new concept for public health practitioners to absorb: a nation dynamically advancing while still attempting to grapple with the legacy of its developing status. By explaining how middle-income countries such as Mexico could simultaneously suffer from high prevalence of infectious and noninfectious diseases, the idea of the “double burden of disease”—exemplified by Mexico—provided a framework for a more data-driven and complex approach to both understanding epidemiology and setting health priorities.

For example in 1988, while serving as the director of the Health and the Economy Project at the private Mexican Health Foundation, Frenk wrote an article in *PAHO Bulletin* criticizing a recent World Bank report for its assumptions about development and health that misinterpreted the epidemiological transition.<sup>138</sup> He wrote that the Bank had mistakenly equated “posttransitional [*sic*] pathology” (noncommunicable diseases) with diseases of the rich and “pretransitional [*sic*]

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<sup>137</sup> Julio Frenk et al, “Health Transition in Middle-Income Countries: New Challenges for Health Care,” *Health Policy and Planning* 4, no. 1 (1989). For other articles by Frenk on the epidemiologic or health transition, see Jose Luis Bobadilla et al., “The Epidemiologic Transition and Health Priorities.” (1993).; Julio Frenk et al., “The Epidemiological Transition in Latin America,” *Adult Mortality in Latin America* 123 (1996).

<sup>138</sup> Julio Frenk, “Financing as an Instrument of Public Policy,” *Health Economics: Latin America Perspectives*, no. 517 (1989).

pathology” (infectious diseases) as diseases of the poor.<sup>139</sup> This notion conflated average development across a nation with sub-national patterns. The Bank, he argued, misconceived the epidemiological polarization occurring in developing countries, such as Mexico. The key distinction to be drawn should be between agrarian, rural economies and industrialized, urban economies.

In both economies, Frenk noted, it was the poor who suffered the most, and the poor who needed more health services, both preventive and curative.<sup>140</sup> For example, he wrote, “no reasonable definition of rich can be stretched to include urban workers barely getting by on minimum wage” or the “armies of unemployed who flock in from the countryside.” The poor in newly industrialized economies had higher rates of “accidents, violence and mental illness.”<sup>141</sup> Poor people suffered disproportionately from what the Bank called “posttransitional pathologies.” This example shows how Frenk used the notion of the “double burden” of disease to carve out conceptual space for noncommunicable diseases as major problems in both developing and developed countries. By offering Mexico’s development as an illustrative alternative to that of the United States, Frenk provided a concrete example aimed at destabilizing false truisms in development.<sup>142</sup>

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<sup>139</sup> Ibid.

<sup>140</sup> Ibid.

<sup>141</sup> Ibid.

<sup>142</sup> Ibid.

In 1989, Frenk founded the Mexican National Institute of Public Health, which provided an even broader platform to set the research agenda. During this time, Frenk developed more conceptual approaches to public health. In an influential paper, he argued that, rather than remaining fragmented in disciplinary silos, public health should integrate multidisciplinary perspectives in considering health problems and look beyond single diseases as the unit of analysis.<sup>143</sup> Frenk advocated dismantling the barriers that separated researchers from decision-makers, which resulted in policies that lacked firm grounding in evidence.<sup>144</sup> Achieving this evidence-based policy, Frenk argued, would represent “true modernization” of public health.<sup>145</sup> This call for evidence-based policy would remain a hallmark of his career across policy, research and political domains.

Through the 1980s, Frenk’s leadership in linking epidemiological and economic approaches to health with conceptual approaches would enable him to navigate the key debates in all those fields. Frenk played a key role in developing, but more importantly, deploying and marshaling for policy advocacy, the quantitative metrics that the Bank and key colleagues would apply to transform global health in the 1990s. While not explicitly related to mental health, Frenk’s

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<sup>143</sup> Julio Frenk, “The New Public Health.”

<sup>144</sup> Ibid.

<sup>145</sup> Ibid.

contributions to public health helped lay the groundwork for a new, ambitious project that would increase the perceived importance of mental health, and establish Mexico as a nation to watch.

### **1.2.5. The Global Burden of Disease Project and Mental Illness, 1993–1998**

In addition to pioneering new conceptual understandings of the epidemiological and demographic transition, Julio Frenk played a key role in conceptualizing and promoting other metrics that would address the problem of measuring mental illness in a population. To address the long-standing difficulty of comparing the amount and severity of disease in and across populations, in 1992, the World Bank commissioned a group of Harvard researchers to develop a universal metric that would compare mortality and morbidity. From 1991–1992, Frenk spent a year as a Visiting Professor at Harvard University’s Center for Population and Studies, and so collaborated on this project.

The project presented the challenge of developing a single metric that could capture both the amount of disability a disease caused and the number of deaths. This project, dubbed the Global Burden of Disease project, took on the challenge of developing how to quantify the effects of disease, or the “burden” it caused. While this effort did not target any given disease, the attempt to quantify morbidity and disability as well as deaths represented a dedication to “objectively identifying epidemiological priorities.”<sup>146</sup> The resulting metric—the disability-adjusted life year or DALY—quantified the burden of disease by adding up years of healthy life lost to both disease and premature mortality. Subtracting the years of healthy life lost due to illness and aggregating across the population, the DALY could quantify the “burden” of

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<sup>146</sup> World Bank, *Global Burden of Disease and Risk Factors*, Washington, D.C., 2006.



disease.

Such efforts culminated in the 1994 publication of the landmark Global Burden of Disease Study (called GBD 1990 because it used 1990 data).<sup>147</sup> Since the DALY combines mortality and morbidity data, employing such metrics caused a host of diseases that cause grave and widespread disability but relatively low mortality—such as diabetes, neurological disorders and mental illness—to rise to the top of the revised rankings of global disease burden. Building on the 1980 attempt to standardize psychiatric diagnoses in the DSM-III, as well as other methodology advances, the DALY suddenly made the task of measuring mental illnesses more feasible.

The result was that the GBD Study upended global measures of the magnitude of mental illness. It found that “in all regions, neuropsychiatric conditions are the most important causes of disability, accounting for more than 37% of YLD [years lost to disability] among adults 15 and older worldwide.”<sup>148</sup> Neuropsychiatric disorders represented five of the top ten diseases in 1990. Reflecting on the impact of the GBD 1990 12 years after its release, the authors noted that this first study “brought the previously largely ignored burden of nonfatal illnesses, particularly neuropsychiatric disorders, to the attention of health policy makers.”<sup>149</sup> (Country-specific

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<sup>147</sup> C. J. Murray, Alan D. Lopez, and Dean T. Jamison, “The Global Burden of Disease in 1990: Summary Results, Sensitivity Analysis, and Future Directions,” *Bulletin of the World Health Organization* 72, no. 3 (1994).

<sup>148</sup> World Bank, *Global Burden of Disease and Risk Factors*.

<sup>149</sup> *Ibid.*

estimates would not be available until Frenk's 2005 *Report Health and the Economy* provided Mexico-specific DALY estimates, discussed below.)

The move toward quantification represented a move toward objectivity and away from subjective measures of health. As the authors of the first publication on the Global Burden of Disease Study noted, the “major justification of the GBD Study was to provide a process through which every disease or health program would be evaluated in a more empirical, replicable and thus, by their definition, objective fashion.”<sup>150</sup> This quest for “objectivity” represented a turn away from the theoretical causes of disease that had predominated in the 1970s—such as the antipsychiatric rejection of mental illness or psychoanalytic etiologies. Yet these claims of objectivity were exactly what critiques of the DALY attacked. Despite the appearance of objectivity conferred by quantification, for critics, the construction of the metric smuggled in social value judgments with ramifications for policy.<sup>151</sup>

The potential use of the DALY for advocacy was explicitly made. As the authors wrote, by also enabling the calculation of a program's cost effectiveness where possible, the GBD Study

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<sup>150</sup> Murray, Lopez, and Jamison, “The Global Burden of Disease in 1990.”

<sup>151</sup> For an example of ethical choices hidden behind a quantitative metric, consider that the DALY incorporated age-weighting, or the “unequal valuation of the time lived at different ages.” Thus the same disease would be considered more of a burden for a young adult than for an older person, and if used for priority setting, would lead to a greater priority placed on treating the young person. The GBD official views on such ethical choices within the construction of population-health metrics such as the DALY has changed over time. For more on ethical concerns with population-health summary statistics, see National Research Council, *Summarizing Population Health: Directions for the Development and Application of Population Metrics*, Washington, D.C.: National Academies Press, 1998.

facilitated more rational resource allocation decisions.<sup>152</sup> (However, this interest in CEA actually undermined prioritizing mental health interventions, which tend to be less cost-effective than other public health initiatives.) Secondly, the authors emphasized that the GBD Study offered concrete evidence that disease advocates could use to strengthen their case. Diseases with the most vocal or eloquent advocates often garner the most attention, the authors noted, while other problems “do not have ready advocates and continue to be ignored.”<sup>153</sup> Thus, the GBD Study boosts in argumentative ability would be of particular aid to advocates of previously neglected diseases (like mental illness).

In addition to raising the profile of psychiatric disorders in general, burden of disease statistics helped expand the populations understood to be in need of mental health policy interventions. In countries like Mexico, where the mental health system remained hospital-based, public policy tended to focus on institutionalized patients, those with severe mental illness, like schizophrenia, who actually represented only a fraction of those with mental illness. As had long been known but not measured, however, the vast majority of people who needed mental health care were not institutionalized. Rather, they were functioning individuals with jobs and families, who tended to suffer from more common illnesses, such as depression, anxiety and substance abuse. Yet even as the problems of public health became more visible, the individuals suffering from them receded into statistical blurriness.

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<sup>152</sup> Murray, Lopez, and Jamison, “The Global Burden of Disease in 1990.”

<sup>153</sup> Ibid.

### 1.2.5.a. Health and the Economy Redux

The DALY had actually made its debut prior to the GBD Study. The first time the Bank's annual *World Development Report* (WDR) focused exclusively on health was 1993.<sup>154</sup> As its title suggests, *Investing in Health* sought to address the basic questions of why government should spend money on health and what the broader payoffs would be of doing so.

This report made the case that reducing poverty and improving health were inextricably intertwined and argued for drawing a strong causal arrow between wealth and health.<sup>155</sup> For example, the data showed that economic indicators, such as GDP, had a strong association with health measures, such as child mortality. This data showed, as the authors argued, that the rise in life expectancy since 1950 had led to the “reduction of the economic burden imposed by unhealthy workers or sick and absent schoolchildren.”<sup>156</sup> Governments need to invest in their health systems in order to assure their continued economic and social development.

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<sup>154</sup> By contrast, as discussed earlier, the 1980 WDR had focused on poverty's relationship to development and discussed health and other social factors as inputs to economic development. World Bank, *World Development Report 1993: Investing in Health: World Development Indicators*, New York: World Bank and Oxford University Press, 1993.

<sup>155</sup> Ibid.

<sup>156</sup> Ibid.

In addition to its broad focus on health, the report argued that policies should target diseases that cause more disability than mortality, because disabling conditions most decreased the economic productivity of workers. Disability, the report declared, is caused by a wide range of diseases, ranging from “polio-related paralysis to blindness to suffering brought about by severe psychosis.”<sup>157</sup> Thus, although not focused on mental health, the 1993 WDR’s emphasis on disability and its connection with lost economic activity set in motion a renewed focus on low mortality-high morbidity diseases. This key change in the logic of what matters most enabled mental health advocates to marshal new arguments in favor of prioritizing mental health. Not only was mental health an important concern for health systems, but the World Bank had also declared its type of disease to be a critical component of overall development.<sup>158</sup>

#### **1.2.5.b. World Mental Health Report 1995**

Mental illness, as one of the main causes of lost productivity in developing countries, warranted attention as never before. In the past, theories of epidemiological transition, such as Omran’s, had emphasized that poor countries were still mostly plagued by infectious diseases and childhood mortality and that noncommunicable diseases only became a problem when countries reached a certain threshold of development. While a few voices, such as Frenk’s, had been

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<sup>157</sup> Ibid.

<sup>158</sup> As an indication of the overlapping visions of health as wealth and health as a moral right, the report combined both. In addition to focusing mainly on economic justifications for enhancing health, *Investing in Health* also explicitly grounded its recommendations in the goal of fulfilling the goals set by WHO’s 1979 “Health for All” campaign.

arguing against this simplistic view for years, the GBD had finally offered hard data that even poor countries had high levels of mental illness.

As a result, a groundbreaking research project began that focused exclusively on the burden of mental illness in developing countries. In 1995, the project yielded the landmark publication *World Mental Health: Problems and Priorities in Low-Income Countries*.<sup>159</sup> Coauthored by leading figures of mental health and international health, including Arthur Kleinman, psychiatrist and medical anthropologist, the book built upon both earlier burden of disease studies and *Investing in Health*. Frenk served on the advisory board.<sup>160</sup> A study prepared by 88 specialists in 30 countries, the book used data from the GBD on DALYs lost to mental illness to substantiate its claims about the enormous burden that mental illness and behavioral problems already placed on developing countries. As coauthor Arthur Kleinman told the *New York Times*, this study refutes “the myth that mental illness was not a problem in the developing world.”<sup>161</sup>

Further, the book rejected the narrow view of mental illness as a collection of biologically based diagnoses (a perception that the growing influence of psychopharmacology had certainly

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<sup>159</sup> Robert Desjarlais et al., *World Mental Health: Problems and Priorities in Low-Income Countries* (New York: Oxford University Press, 1995).

<sup>160</sup> In the acknowledgments, Kleinman singled out eight of the 31 members of the WMHR’s Advisory Board for “going beyond the call of duty” in deliberating about concerns with the report. Desjarlais et al., *World Mental Health*.

<sup>161</sup> Barbara Crossette, “Mental Illness Found Rising in Poor Nations,” *New York Times*, May 16, 1995.

encouraged). Rather, the opening words of the report made clear that mental illness involved myriad social factors beyond individual biochemistry: “World mental health is first and foremost a question of economic and political welfare.”<sup>162</sup>

President Jimmy and Mrs. Rosalynn Carter penned the book’s foreword, praising the WMH report for tackling longstanding framing of mental illness exclusively in terms of diagnoses made in the developed world (as Levav and Alarcón had done earlier).<sup>163</sup> Such narrow views of mental illness, they argued, can never measure the psychological ramifications of many aggravating sociodemographic aspects of life in developing countries. Among the problems with such an approach, the Carters wrote, included wrongly classifying social problems and failing to recognize their impact on mental health. The consequences of such erroneous approaches would include treating substance users as criminals, domestic violence as an issue of criminal justice, refugees as a political concern, and natural disasters as a topic for technical expertise without

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<sup>162</sup> Robert Desjarlais et al., *World Mental Health: Problems and Priorities in Low-Income Countries* (New York: Oxford University Press, 1995).

<sup>163</sup> Ibid.

acknowledging the psychological harms these various problems cause.<sup>164</sup> Poverty, discrimination and high unemployment are all conditions exacerbated by the problems of mental illness.<sup>165</sup>

To maximize the impact of the study's publication, the authors held a launch party for the formal release of the book at the United Nations Headquarters in New York City.<sup>166</sup> The bid for attention worked: then Secretary General of the United Nations Boutros Boutros-Ghali, personally presided over the launching ceremony.<sup>167</sup> In his address, Ghali declared "this report puts the issue of mental health and well-being firmly on the international agenda... Let us, therefore, respond to this *World Mental Health* Report not simply by blessing it; let us take its recommendations, and act on them."<sup>168</sup> An Indian economist in attendance told a *New York Times* reporter covering the event that he agreed with the report's emphasis on the social context

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<sup>164</sup> Ibid.

<sup>165</sup> For more on the substantive arguments in the World Mental Health Report, see Leon Eisenberg, "Psychiatry and Health in Low-Income Populations," *Comprehensive Psychiatry* 38, no. 2 (0, 1997), 69-73.

<sup>166</sup> Interview with Arthur Kleinman, July 2011.

<sup>167</sup> Crossette, "Mental Illness Found Rising in Poor Nations."

<sup>168</sup> Boutros Boutros-Ghali was so moved by WMHR that he soon after launched a new program on mental health in developing countries. J. Orley, "World Health Organization: Programme on Mental Health," *Journal of Mental Health* 5, no. 3 (July 1, 1996).



of mental illness. In fact, he asserted that to “continue to ignore mental illness would not only impede economic growth, but would even undermine democracy.”<sup>169</sup>

#### **1.2.6. Dr. Frenk Goes to Geneva: Evidence-based Policy for Mental Health, 1998–2000**

In July 1998, Julio Frenk moved quickly from Mexico to Geneva to assume a new position at the World Health Organization (WHO), as Director of the newly formed Evidence and Information for Policy Cluster.<sup>170</sup> This new title reflected his 20-year push for evidence-based policy and advocacy. Further, both his selection and his eventual work while in this role resulted from key personnel and mission-related changes within the WHO.

Earlier that year, former Norwegian prime minister and public health-oriented physician Gro Harlem Brundtland had become the WHO’s new Director-General. When, in May 1998, she gave her inaugural speech to the World Health Assembly, she declared that “malaria, tobacco and a “serious look at mental health” would be her top priorities.”<sup>171</sup> This fierce commitment stemmed from personal tragedy. On September 24, 1992, Brundtland’s youngest son, 25-year-old Jorgen, had committed suicide after years of battling manic depression since his diagnosis at

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<sup>169</sup> Crossette, “Mental Illness Found Rising in Poor Nations.”

<sup>170</sup> Interview with Julio Frenk, July 2010.

<sup>171</sup> Dr Gro Harlem Brundtland, *Speech to the Fifty-First World Health Assembly* (Geneva, Switzerland: , 1998).

age 17. In her 2005 autobiography, Brundtland expressed outrage that a rich country such as Norway would not have “a real treatment or support system to offer young people faced with such severe psychological problems.”<sup>172</sup> Jorgen’s suicide seared into Brundtland’s mind the need to reform mental health systems worldwide. Six years later, her new position would empower her to do just that.

One of the explicit reasons Frenk became one of Brundtland’s cabinet members was her initiative to clean up the declining reputation of the WHO. She had taken office at a time when, in her words, the organization had gained a reputation as “unfocused, even corrupt and overrun by middle management.”<sup>173</sup> To strengthen the organization, she decided to broaden its leadership. Instead of drawing her cabinet from the restricted set of nations that comprised the Security Council, she strategically and deliberately filled her cabinet with nationals from a wider range of countries, including Mexico. As Frenk laughingly recalled in 2011, Brundtland’s plea to join her cabinet was so urgent, so urgent that she rejected his request to move later in order to ease the transition for his family.<sup>174</sup> He packed up and flew alone.

Once Frenk was installed in Geneva, Brundtland informed him that mental health would be the focus of the 2001 World Health Report. This choice marked the first time the report would focus

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<sup>172</sup> Gro Harlem Brundtland, *Madam Prime Minister: A Life in Power and Politics*, New York: Farrar, Straus & Giroux, 2002.

<sup>173</sup> Gro Harlem Brundtland, *Madam Prime Minister: A Life in Power and Politics* (New York: Farrar, Straus & Giroux, 2002), 485.

<sup>174</sup> Interview with Julio Frenk, June 2011.

on mental health. With three years to prepare, Frenk set to work. The director of the Department of Mental Health and Substance Abuse, Italian psychiatrist Benedetto Saraceno, led his team in preparing the report under Frenk's leadership.

The second major initiative Brundtland undertook arose from the first. Just as the health-wealth debate had led to the creation of the DALY in the early 1990s, a similar push to explore the relationship between economics and health compelled Brundtland to embrace the DALY as the official global health metric of the WHO.<sup>175</sup> A few precedents had led to this decision. In 2000, the principal architect of the GBD project, Christopher J. L. Murray, had issued an updated version of the GBD report and had briefed Brundtland on the changes. Yet the choice to adopt the DALY was not an uncomplicated decision for the WHO. Frenk would later recall:

[B]efore then, the WHO didn't want anything to do with DALYs. This was, politically, an exercise that started at the World Bank, and the WHO and academia felt extremely threatened by the World Bank taking the lead, there was no way that the WHO would even talk about DALYs.<sup>176</sup>

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<sup>175</sup> During her tenure as Director-General, Brundtland grew increasingly interested in the role of social determinants to influence health beyond medicine and traditional public health. She invited Amartya Sen to speak about the connection between poverty and health. She then asked Jeffrey Sachs to start the Commission on Macroeconomics and Health, whose 2005 report opened a new dialogue on the moral and instrumental relationship between health and wealth. J. D. Sachs, *Macroeconomics and Health: Investing in Health for Economic Development* (World Health Organization, 2001).

<sup>176</sup> Frenk's opinion on this issue must be considered in light of the fact that the GBD study had been a joint initiative of the WHO, WB, and Harvard. The WHO had used the DALY for almost a decade at that point, so whether this was mostly a symbolic change must be considered. Interview with Julio Frenk, June 2011.

Brundtland decided to set aside such institutional rivalries in light of the DALY's ability to illuminate aspects of disease burden that would otherwise remain invisible, by virtue of being immeasurable.

This institutional change, as had the GBD Study before it, had a dramatic impact on the specific issue of mental health. As Frenk noted in 2011, the timing of the WHO's adoption of the DALY was particularly fortuitous for his own work, since his World Health Report on Mental Health was due the following year. Frenk claimed that this switch had:

revolutionized the way we think about priorities...because once you include loss of deaths not only due to premature mortality, but also to disability, then mental health rises to the top. The very top cause of loss of DALYs.<sup>177</sup>

Proponents of the DALY, such as Frenk and Brundtland, celebrated its ability to prioritize what mattered morally. The push to quantify mental illness, Frenk argued, represented an explicit attempt to restore the proper moral significance of the problem in the eyes of the world. By describing health in neutral terms, as Frenk noted in 2011, this “technocratic, epidemiologic” approach to prioritizing mental illness amounted to “essentially the opposite of the antipsychiatry movement.”<sup>178</sup> While the antipsychiatrists had decried abuses of psychiatric asylums in stark terms of outrage, the new metrics strategically removed the effect of both the social and political

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<sup>177</sup> Interview with Julio Frenk, June 2011.

<sup>178</sup> Ibid.

dimensions of the illness. The goal was to strip away destructive biases and misunderstandings that obscured its importance.

This new medicalization seemed to offer a counterpoint to, if not a cure of, stigmatization.<sup>179</sup> In recalling Brundtland's decision, Frenk described her strategy of combating stigma by replacing moral views with a more biological perspective:

[Brundtland] was saying, "We have to medicalize mental illness...because when you demedicalize it then people start thinking that this is maladaptation, or this is not a disease. Then it does not get diagnosed, it doesn't get treated and people commit suicide."<sup>180</sup>

In the past, proponents of the biological model of mental illness, such as de la Fuente, had not been advocates of system-wide overhauls. If mental illness were located in the brain, rather than in society, treating it would require better medications and therapeutics. By contrast, the sociopolitical interpretation of mental illness had been the purview of reformers, such as the antipsychiatrists, who saw psychiatry and its diagnostics as arms of the state, and later reformers, such as Arthur Kleinman, who emphasized the economic, political and social context of mental illness. Now Brundtland recombined these motifs into something new by championing the

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<sup>179</sup> Of course, this was not the first time that stripping disease of its social context offered the possibility of removing negative moral interpretations. (In the early twentieth century, the rise of the asylum with its biological treatments and the move away from "moral cures" had similarly seemed to offer a more humane alternative that removed blame from the patient.)

<sup>180</sup> Interview with Julio Frenk, October 2011.

biomedical model to push for a societal revolution in perceptions of mental illness. The timing for this change was right. The WHO's (and Brundtland's) neo-biological approach fit with the 1990s global explosion of cultural, as well as scientific, interest in the brain.

During the 1990s, new advancements in brain sciences led many to view biological research, rather than a strict social or political interpretation of mental illness, as the way forward. In the United States, President George H. W. Bush had declared with great fanfare that the 1990s would be the “Decade of the Brain.” In 1993, the landmark bestseller *Listening to Prozac* spoke to and documented a society wrestling with the meaning of the new psychotropic drugs, not only for the severely mentally ill, but also for mostly functional individuals. While the resulting social dialogue questioned what drugs such as Prozac implied about the self, the overall impact was that brain-based analyses of mental illness once again seemed advanced, not antiquated.<sup>181</sup>

In addition to the advances in neuroscience, the negative and visible consequences of deinstitutionalization (though not in Mexico) also contributed to this shift in attitude. By removing walls and bars and physical restraints, deinstitutionalization had—perhaps unexpectedly to the reformers of the 1970s—created a new societal acceptance of medications. Rather than the asylum's lobotomies or insulin-induced comas, medical treatments now included effective, relative safe medications that restored individuals' ability to function in the community.

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<sup>181</sup> Peter D. Kramer, *Listening to Prozac*, New York: Penguin Books, 1997.

Reflecting on the global failure to prioritize mental illness, Frenk further explained Brundtland's decisions to make it part of her platform. As Frenk explained,

[Brundtland's] perspective, once she rationalized it, was that this has been the failure of the health system. And that this had to do with the stigma of mental illness, and how they refused to call this an illness. So if anything she was virulently opposed to Thomas Szasz.<sup>182</sup>

Yet Brundtland's choice to "officialize the DALY," according to Frenk, represented a view about mental illness no less forceful than Szasz's. She wanted to declare, he explained, that mental illness "is a disease. It is *not* maladaptation, it is *not* [the result of] social forces or marginalizing people. It is a *disease*, it has a biological foundation and it has to be treated."<sup>183</sup> Now the impulse for reform derived from a passionate assertion of mental illness as a disease.

#### **1.2.7. Back to Mexico: 2000**

Tracing Julio Frenk's career from the completion of his PhD in 1983 to the dawn of his term as Minister of Health in Mexico in 2000 reveals the series of developments in public health, both conceptual and methodological, that culminated in the appearance of mental health as a global health priority in the late 1990s. Despite his relative silence on mental health issues between 1983 and 1997, Frenk's move to a systems-level perspective paradoxically led to greater

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<sup>182</sup> Interview with Julio Frenk, October 2011.

<sup>183</sup> Ibid.

visibility and prioritization for mental health than did his targeted activist, asylum-based efforts of his 1970s medical student days.

By the turn of the twenty-first century, the GBD Study and follow-up projects seemed to have prepared the way for global prioritization of mental health. As Arthur Kleinman recalled in 2010, these positive developments led to a great sense of optimism among global mental health proponents.<sup>184</sup> For Frenk, this virtuous cycle of research and advocacy seemed to vindicate his general call for evidence-based policy and advocacy.<sup>185</sup> However, in Mexico, the mental health system remained as hospital-based as it had been at the start of the 1980s.<sup>186</sup>

Julio Frenk himself took up a renewed attempt at Mexican national health reform, this time as a political insider for the first time. In 2000, prior to the 2001 publication of the World Health Report on Mental Health, he suddenly returned to Mexico. The urgency came from a historical opportunity. After 70 years of single-party rule, Mexico had elected a new president from a different party, Vicente Fox, who in turn named Frenk as his Minister of Health.

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<sup>184</sup> Interview with Arthur Kleinman, July 2011.

<sup>185</sup> Interview with Julio Frenk, October 2010.

<sup>186</sup> In 1991, new legislation had passed that protected the rights of psychiatric patients, at least on paper.



**PART III**  
**From Theory to Practice:**  
**Minister Frenk and the Politics of Mental Health,**  
**2000–2006**

**1.3. Inside the Government**

When Frenk assumed the role of Mexican Minister of Health in 2000, the political moment seemed right for dramatic changes in the country's health system.<sup>187</sup> The 2000 election of President Vicente Fox of the National Action Party (PAN) had been historic: the first democratic presidential election in Mexican history, it had ended over 70 years of continuous single-party rule by the Institutional Revolutionary Party (PRI).<sup>188</sup> During his campaign, Fox ran on an “American-style” platform of real reform. He promised to eliminate the cronyism that had characterized the previous seven decades of PRI administrations. Specifically, Fox vowed to include political outsiders, such as technical experts and even civil society leaders, in his cabinet.<sup>189</sup>

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<sup>187</sup> For more on this historic 2000 presidential election, see Shirk, *Mexico's New Politics*; and Richard Snyder, *Politics after Neoliberalism: Reregulation in Mexico*, Cambridge, U.K.; New York: Cambridge University Press, 2001.

<sup>188</sup> PRI is the Institutional Revolutionary Party (*Partido Revolucionario Institucional*). PAN is the National Action Party (*Partido Acción Nacional*).

<sup>189</sup> Jason Lakin has argued that in addition to Fox's desire for more technical expertise and less political cronyism in his government, other more practical motives also drove him to fill his cabinet with technical experts. Since PAN had not been in power for decades, at the time of the election, it did not have a ready pool of bureaucrats from which to select a cabinet. The outsiders

By appointing Julio Frenk as Minister of Health, Fox helped fulfill this campaign pledge to include political outsiders. His choice also represented the administration's explicit commitment to evidence-driven, non-political approaches to policy. Not only was Frenk a physician and a renowned international leader in global health, who had been living outside Mexico before the election, he was also a non-politician who had never been affiliated with any political party.<sup>190</sup>

Examination of Frenk's six years as Minister of Health provide a window into the political challenges of implementing his own vision of evidence-based policymaking in Mexico. For the first time, he seemed to have the power to enact real policy changes in Mexico. But even as Frenk succeeded in making important changes to the Mexican health system as a whole, his efforts to reform the mental health system floundered. Deservedly, his success at passing landmark health system reform has garnered a great deal of attention from academic and non-academic sources. Yet the less glorious narrative of Frenk's attempts at mental health advocacy during his time in office as Minister of Health reveals, more than in any other era of his career, the fundamentally political nature of policy reform. More specifically, reconstructing the narrative demonstrates the power of non-evidence-based factors—the entrenched nature of political corruption and special interests, the opposition of establishment figures and the absence of coherent outside pressure—all colluded to impede psychiatric reform in Mexico.

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became insiders on purpose and by necessity. See Lakin, "The Possibilities and Limitations of Insurgent Technocratic Reform."

<sup>190</sup> Interview with Julio Frenk, July 2010.

When Frenk left the WHO to return to Mexico, he intended to use his experience as a champion of evidence to push for long-awaited reforms to the Mexican mental health system. Under his leadership, the 2001 World Health Report on Mental Health had illuminated mental illness as a major contributor to the global burden of disease. Yet just as the visible failures of the asylum model in the late 1970s had failed to translate into well-functioning community-based mental health systems, so too did translating these findings into policy and programmatic changes remain elusive.

Once appointed, Frenk seized the opportunity his office provided to push through changes to the Mexican health system as a whole. The dramatic upheaval in the political landscape post-2000 enabled Frenk to propel profound overhauls in the Mexican health system, most importantly his development and implementation of Seguro Popular (“Popular Health Insurance” in English). Seguro Popular is a health benefits scheme designed to provide health coverage to the 50% of Mexicans who had neither private health insurance nor coverage through one of the government social security plans.<sup>191</sup> In 2003, after long political and technical debates, the Mexican Congress approved Seguro Popular, and its rollout began in timed stages.<sup>192</sup> As an innovative policy initiative seeking to cover uninsured populations in developing countries, Mexico’s Seguro Popular has attracted a great deal of international

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<sup>191</sup> The eventual design of *Seguro Popular* resembled both Frenk’s vision of an integrated model of public health that he had earlier articulated in his 1993 article “New Public Health,” as well as the detailed calls for health system reform he proposed in his 1995 *Economy and Health* report, as discussed in Part II.

<sup>192</sup> For more on Frenk’s role in the strategic process of making *Seguro Popular* politically palatable, see also Lakin, “The Possibilities and Limitations of Insurgent Technocratic Reform.”

analysis in the years following its approval and implementation and has attracted both criticism and praise.<sup>193</sup>

In the years following Fox's election, the growing openness to civil society in policymaking raised the volume on mental health advocacy in this slowly strengthening democracy.

However, Seguro Popular aimed to revolutionize the entire health system, not just the Mexican psychiatric system, or any other single disease. Frenk reported in 2010 that during the early years of Seguro Popular, he had difficulty communicating the idea behind the new benefits package to single disease advocates. "Seguro Popular," he recalled, trying to explain, "is the vehicle and the single diseases are the passengers."<sup>194</sup> The fact that it did not focus entirely on one disease did not mean that it ignored that disease. Rather, he described, the vision involved a more fundamental overhaul that would improve coverage of many diseases. He tried to make the diseases' advocates understand, he said, that Seguro Popular was "not just another line item

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<sup>193</sup> Lakin called the passage of Seguro Popular an example of "insurgent technocratic reform." It was insurgent because the push was directed by a cell or change team rather than by a broad support base, and had no major political allies. It was technocratic because the change agents were "educated functionaries" rather than "elected politicians" and used the language of science rather than political ideology to advance their views. For more on the political history of Seguro Popular, see Lakin, "The Possibilities and Limitations of Insurgent Technocratic Reform." See also Nathan Paxton, "Learning to Live? Examining Differential International Responses to HIV/AIDS," PhD diss., Harvard University, 2009.

<sup>194</sup> Interview with Julio Frenk, October 2010.

to be approved in the Congress, but a fundamental reform of financing of the whole health system.”<sup>195</sup>

Yet these explanations did not satisfy many mental health reformers. For example, as a general health insurance, Seguro Popular covers a broad range of conditions and treatments. Yet mental health remained underfunded, according to former antipsychiatric activist Carlos Rodríguez

Ajenjo, who was then head of the Ministry of Health’s Substance Abuse department when interviewed in 2010. For example, he said, Seguro Popular provides only minimal coverage of antidepressant and some antipsychotic medications.<sup>196</sup> This disparity in coverage led some in the mental health field to view Frenk as having abandoned the cause. During a 2010 visit to the principal psychiatric hospital in Mexico City, psychiatrist Dr. Raoul Fournier addressed Frenk’s earlier career interest in mental health in relation to his actions as minister. “If he cares about mental health,” Fournier asked, why did Julio Frenk abandon the issue?”<sup>197</sup>

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<sup>195</sup> Ibid.

<sup>196</sup> Nevertheless, this list of covered diseases or treatments has been expanding and is reviewed by a national council every three months. Interview with Carlos Rodríguez Ajenjo, July 2010.

<sup>197</sup> Interview with Dr. Hector Fournier, Mexico City, July 2010. During the same site visit, Dr. Carlos Castañeda, Director of Fray Bernardino Álvarez Hospital, reported that the historical neglect of mental health in the Mexican health system has one ironic upside. While other areas of health have come increasingly under the control of administrative oversight, the mental health system has been ignored. Interview with Carlos Castañeda, July 2010.

Some in the mainstream media also criticized Frenk in the name of championing mental health reform. One of Frenk's most vocal detractors in this area was newspaper columnist Jaime Aviles. In his column in the newspaper *La Jornada*, Aviles wrote a series of scathing indictments of Frenk's record on mental health. Not only did Frenk fail to do enough to improve conditions in the asylums, Aviles also accused him of becoming a "traitor to his earlier values" now that he was part of the government.<sup>198</sup> For his part, in an interview in 2010, Frenk denied the accusation that he ignored mental health. Instead, he argued that simultaneous to attempts to implement *Seguro Popular* his team was also trying to improve mental health coverage through the decentralization of resources.<sup>199</sup>

In fact, it was under Frenk's term in office that Mexico issued a five-year mental health plan for the first time. This report, titled "Master Plan in Infrastructure for Mental Health Care in the State of Mexico and the Federal District, 2001–6," described the Ministry's vision for mental health policy and programs over the remaining years of the Fox administration.<sup>200</sup> Just as the World Health Report had detailed the burden of mental illness worldwide, so too did the national plan present a systematic examination of Mexico's mental health system across

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<sup>198</sup> For an overview of Avilés' journalistic work around psychiatric reform, see Avilés, *Los Manicomios del Poder*.

<sup>199</sup> Interview with Julio Frenk, July 2010.

<sup>200</sup> Secretaria de Salud, *Programa De Accion En Salud Mental* (Mexico City, DF: Secretaria de Salud,[2001]).

several dimensions: epidemiological patterns, economic burdens, programmatic challenges and treatment options. Yet, this report would attract its own share of scrutiny from within Mexico

### **1.3.1 Calling in Outsiders: Evaluation of Mental Health Services in Mexico**

In 2002, faced with criticism both from activists and the conservative psychiatric establishment, Frenk sought assistance from outside Mexico. In Frenk's political calculation, the conservative psychiatric establishment would not respond to him, and his ministry lacked the power to reform the system without its support. Without outside pressure, the psychiatrists would not have any incentive to budge on reform issues. In 2002, Frenk commissioned his former colleagues at the WHO to conduct an evaluation of Mexico's mental health system. For that purpose, in 2002, Frenk invited a team of well-respected international experts, many his former colleagues from the WHO, to fly from Geneva to Mexico to undertake an external evaluation.<sup>201</sup> He wanted the team to personally witness, and hopefully condemn, the Mexican psychiatric system so as to build political momentum for reform.

Along with the WHO, PAHO also participated in the evaluation. It had its own historical reasons for wanting to encourage psychiatric reform in Mexico. Following the 1991 Declaration of Caracas, in which Latin American countries had pledged to move away from asylums and custodial care toward community-based mental health services, insufficient action had occurred in PAHO's opinion. Thus, participating in this new exposé of the Mexican system offered the opportunity to renew the initiative to reengage the spirit of Caracas. Mexico's huge population

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<sup>201</sup> The WHO's efforts were assisted by the regional office of PAHO, which at that time had an office in Mexico City. Interview with Carlos Rodriguez Ajenjo, July 2010.

and influence meant that real reform there would likely encourage smaller countries in the region to resume their own reform efforts.<sup>202</sup>

The evaluators who came to Mexico were led by Dr. Benedetto Saraceno, the Italian psychiatrist in charge of the WHO's Department of Mental Health, who had been Frenk's colleague during the preparation of the 2001 World Health Report on Mental Health. As Saraceno recalled in 2010, the intractability of the Mexican psychiatrists and their opposition to reform was one of the most vitriolic he had encountered in his years as an international mental health expert. "They were the most conservative, the most opposed to change," he reported.<sup>203</sup> Nevertheless, the team continued to visit asylums around the country and to document what they found.

The resulting report, "Evaluation of the Mexican Mental Health System," provided the scathing yet measured critique that Frenk had been hoping for when he commissioned the evaluation. The researchers denounced the lack of psychiatric reform in Mexico:

The pillar of the system still is the psychiatric hospital, with all the observed deficiencies and elevated costs. Almost all hospitalizations and the majority of ambulatory activities are offered in psychiatric hospitals, instead of a general hospital or in the community.<sup>204</sup>

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<sup>202</sup> Interview with Carlos Rodriguez Ajenjo, July 2010.

<sup>203</sup> Telephone interview with Benedetto Saraceno, July 2011.

<sup>204</sup> Organizacion Panamericana de la Salud, *Evaluacion De Servicios De Salud Mental En La Republica Mexicana* [Evaluation of Mental Health Services in the Republic of Mexico] (Mexico, D.F.: Organizacion Panamericana de la Salud, 2004).



The researchers declare that in order to live in the community, people with severe mental illness need what any other citizen needs: “a place to live, an occupation, and the opportunity to carry out leisure-time activities that contribute to their social integration.”<sup>205</sup>

Community-based services remained woefully lacking, the evaluators wrote. In order “to replace the custodial model of treatment...in the opinion of the experts, the major challenge lies in being able to develop quality community-based resources.”<sup>206</sup> Including beds for psychiatric patients in general hospitals had long been recognized as one method to improve integration of services. Yet, resistance on the part of the general hospitals, and often local communities, blocked such initiatives, such that most psychiatric beds remained segregated in psychiatric hospitals, usually far from city centers.

In keeping with the decades of critiques of the Mexican mental health system, the evaluators criticized the Mexican Mental Health Plan for promoting new construction of psychiatric hospitals rather than community mental health programs. They argued “it would be premature to speak of construction or renovation of psychiatric hospitals to provide more beds for psychiatric patients.” Without services in the general hospitals, clients have difficulty accessing “community-based follow-up,” since their hospitalizations “take place in distant psychiatric

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<sup>205</sup> Ibid.

<sup>206</sup> Ibid.

hospitals and for increasingly prolonged periods.”<sup>207</sup> Thus, the emphasis and the primary investments should be in programs, not buildings.”<sup>208</sup>

Yet the evaluators recognized the historical symbolism of building new institutions and how unveiling new asylums had long served as a public relations tool for Mexican psychiatry. Noting “the danger of mere transinstitutionalization,” the authors warned that “if practices are not changed first before infrastructure, whatever new structure that is built runs the risk of becoming an asylum.” In a similar vein, historian of Mexican psychiatry Cristina Sacristan has referred to this “great faith in institutions as bearers of change in themselves” as being part of Mexico’s historical inheritance. She explains the cycle of construction and decline thus:

Attacking existing institutions to justify their closure and the opening of others creates a sense of inaugurating a new era in mental health...The state celebrates the opening of new institutions believing that in these lie the solutions to the nation’s problems, but once established, the state abandons them and they fall into disrepair only to be founded again. Later the cycle will repeat. Until when?<sup>209</sup>

In addition to the distracting spectacle of building and rebuilding new institutions without transforming basic programs, the evaluators noted other problems with the facilities they visited. During their site visits, for example, evaluators witnessed that the labor force remained overwhelmingly medical, “leaving the other service members in a secondary and auxiliary

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<sup>207</sup> Ibid.

<sup>208</sup> Ibid.

<sup>209</sup> Ibid.

role.”<sup>210</sup> The “complete lack of psychosocial services apart from those clearly medical is striking,” they wrote. Nor could Mexico hide behind the defense that poverty prevented real change. “The problem is not, in essence, a question of the lack of resources. There is a lack in some places, but there are others in which resources are not well used.”<sup>211</sup>

The evaluators also recommended political changes to smooth the path toward policy changes. As part of the Fox administration’s stated goals of opening Mexico and increasing democratization, the authors made a call for transparency in the form of a public discussion of the 2001–6 Master Plan with a range of stakeholders, including patients, politicians and decision makers at the Secretary of Health.<sup>212</sup>

### **1.3.2. The Battle of Hidalgo: Frenk, Gonzalez and Mental Health Delivery**

In addition to attacking and condemning the status quo, some sought to develop positive alternatives to the terrible conditions such as those described by the international evaluators. One of the sources of agreement and friction between Frenk and more radical mental health reformers, such as Virginia Gonzalez Torres, arose over what model of reform to promote. In 2000, in the wake of the successful closure and demolition of the Ocaranza Hospital, she had founded a new model of mental health delivery built on the grounds of the old site. She called

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<sup>210</sup> Ibid.

<sup>211</sup> Ibid.

<sup>212</sup> Whether or not such public engagements ever took place remains unclear.

this approach the Hidalgo Model (*Modelo Hidalgo*) after the former hospital's location in the state of Hidalgo. (The WHO evaluation had given the Hidalgo Model a cursory, yet positive review.)

Promoting the Hidalgo Model quickly became Gonzalez Torres' leading cause. This model of mental health service delivery aims to promote community-based, decentralized mental health services. Initially, Secretary Frenk and Gonzalez Torres seemed to be in agreement about the value of the model. In November 2000, his first year as Secretary of Health, Frenk made an official visit to Hidalgo to show support for Gonzalez Torres' success at closing the Ocaranza Hospital and her then-fledgling attempts to develop an innovative model of care for Mexico. Later, in 2003, Frenk spoke to reporters about his commitment to the Hidalgo Model, praising it as a viable alternative to the status quo, which remained one of asylums in many parts of the country. In an interview with the *New York Times*, Frenk declared that by "2006, the government hopes to establish similar mental health systems in every state and close its 18 government hospitals."<sup>213</sup>

That goal was never reached. Journalist Jaime Aviles began to call Frenk a traitor to his own earlier values, even those he expressed as recently as during his time in Geneva, before joining the Fox administration. Aviles called it a battle between Julio Frenk and "Polonius Frenk."<sup>214</sup> In

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<sup>213</sup> Miguel Xavier, "Mexico: The Hidalgo Experience: A New Approach to Mental Health Care," in *Innovative Mental Health Programs in Latin America and the Caribbean*, eds. Caldas de Almeida, Jose Miguel and A. Cohen (Washington, DC: Pan American Health Organization, 2008), 93.

his 2006 book about this recent history of the scandal and aftermath, Aviles recalled fondly an interview he had conducted with Frenk in 1978, in which the then-activist medical student had expressed passionate support for the decriminalization of marijuana. Regretfully, however, now that he was Secretary of Health, Aviles complained, Frenk had turned his back on such progressive stances.<sup>215</sup>

Worse, according to Aviles, Frenk seemed to be in cahoots with immoral criminals. In 2003, evidence arose that the Sub-Secretary of Mental Health (and Frenk appointee) Guido Belsasso had tried to sell political favors in exchange for bribes.<sup>216</sup> Though unrelated substantively to the mental health system, when this scandal hit the news, the fact that Frenk remained strangely quiet about the fall of his appointee gave skeptics fuel to paint him as one of the conservative obstructionists of reform.

The Belsasso case provided Aviles with a martial metaphor to characterize psychiatric reform. “The battle for psychiatric reform developed between June and August of 2003,” Aviles wrote, dividing the world into two clear sides: those in favor of the Hidalgo Model and those opposed to it. On the good side, those who favored the Hidalgo Model included “the WHO, and some private associations of Latin America, Europe and the United States.” On the bad side, Aviles

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<sup>214</sup> Jaime Aviles, "Julio Frenk Vs. Polonio Frenk," *La Jornada*, sec. Politicas, June 28, 2003, 2003.

<sup>215</sup> Ibid.

<sup>216</sup> Ibid.

noted, were “doctors, clients, and workers of the Granja Samuel Ramirez Moreno, Julio Frenk, Vicente Fox and his wife, who tried to impede the fall of Belsasso.”<sup>217</sup> The political scandal regarding Belsasso and the policy position regarding the Hidalgo Model became equated in this all-or-nothing version of events. Frenk, thus, emerged as an enemy of psychiatric reform because he did not immediately speak out regarding the Belsasso case.

The so-called battle over psychiatric reform not only concerned the scandalous activities of Belsasso himself, or even the value of specific policies. It also played out in economic terms, as Belsasso’s requests for budgetary allocations came under fire as symbols of distorted priorities. Writing in *La Jornada*, Aviles criticized Belsasso, who had asked for 521,232,500 pesos to expand and strengthen the network of asylums (that Aviles noted are so “lamentably administered”).<sup>218</sup> Of this total budget, 70.3% would help construct new asylums, 27.3% would remodel existing ones, while only 2.4% would go to building community mental health modules.<sup>219</sup> This breakdown of priorities represented a complete reversal of the appropriate goals for mental health reform. The bulk of the money should be spent on expanding community mental health practice, not toward building or remodeling existing asylums. The Master Plan for Mental Health, in other words, did not aim to overhaul Mexico’s defunct mental health system,

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<sup>217</sup> Ibid.

<sup>218</sup> Ibid.

<sup>219</sup> These percentages break down to 366,426,448 pesos, 143,338,938 pesos, and 12,509,580 pesos, respectively.

but rather represented Belsasso's goal to modernize the old asylum system with a massive investment of 500 million pesos.

"In spite of the fact that the advice of the WHO is that mental health ought to be moved out of the psychiatric hospitals," Aviles ranted, "the 'public enemy of psychiatric reform in Mexico' [Belsasso] plans to direct zero pesos and zero cents (0.0%) to the development of community programs."<sup>220</sup> Aviles reserved additional condemnation for Belsasso's boss for not stopping this blunder:

If Julio Frenk would take a good look at this crazy amount, he would see that the country would take many years to recover from the blow and this step backward would have grave consequences in the field of teaching because the new generations of psychiatrists will be trained in this despotic manner, without appreciating the human rights of the mentally ill, and without alternatives in the new treatments than have demonstrated their efficacy and quality.<sup>221</sup>

Aviles was not alone in his attack on this budgetary plan. While Gonzalez Torres also clashed with Belsasso about the investment in new asylums, she reserved a particularly acute sense of disappointment with Frenk for not getting more involved in the struggle over the proper vision for mental health reform. It is a "shame that Julio Frenk kept himself on the sidelines," she told Aviles, "Why? What was the reason for his silence?" Particularly, she criticized Frenk's lack of passionate activism and his bureaucratic, bloodless approach to pushing for reform. Frenk "is a

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<sup>220</sup> Jaime Aviles, "Julio Frenk Vs. Polonio Frenk," *La Jornada*, sec. Politicas, June 28, 2003, 2003.

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<sup>221</sup> Ibid.

genius,” she complained. Therefore, it is “such as shame that he doesn’t want to roll up his sleeves and get into the ring. He tries to do everything from his desk and that can’t be done.”<sup>222</sup>

In fact, Frenk’s first action in the wake of the Belsasso scandal was to appoint Gonzalez Torres as the Technical Secretary of the newly formed Council on Mental Health. After decades of acting in parallel or butting heads over the same goals, and instead of continuing to clash with Gonzalez Torres, Frenk decided to make her an ally by bringing her into government. In addition to running the major free mental health clinic in Mexico City, she has made the dissemination of the Hidalgo Model of mental health care the hallmark *raison d’etre* of the Council, though that had not been its explicit mission as defined by Frenk.<sup>223</sup> Long after Frenk’s term as Minister of Health ended in 2006, she continues to play the role of the radical activist, albeit one now operating as a government functionary.<sup>224</sup>

In 2010, DRI—the same group that had written the scathing 2000 report of Mexico’s psychiatric facilities and judged them as the “worst in the world”—returned to carry out an updated report of

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<sup>222</sup> Jaime Aviles, "Julio Frenk Vs. Polonio Frenk," *La Jornada*, sec. Politicas, June 28, 2003, 2003.

<sup>223</sup> When asked about the role played by Virginia Gonzalez Torres as head of the Council, Rodríguez Ajenjo replied that “she did much more as a member of civil society than she has as a governmental functionary.” Interview with Carlos Rodríguez Ajenjo, July 2010.

<sup>224</sup> Through its Web site, <http://www.consame.salud.gob.mx>, the Council asks for denunciations (*denuncias*) of other Secretary of Health facilities that do not respect patient rights.



where Mexico's mental health system now stood after a decade.<sup>225</sup> Notably, their Mexican partner in this investigation was not affiliated with the Ministry of Health, or even with any other medical or public health entity. They found the conditions mostly unchanged and Eric Rosenthal, MDRI's director, described the conditions as "atrocious and abusive."<sup>226</sup>

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<sup>225</sup> Disability Rights International was formerly Mental Disability Rights International, which was their name when they conducted their 2000 report, *Human Rights and Mental Health: Mexico*. As described in the 2010 report, DRI "is an international human rights organization dedicated to the rights and full participation in society of people with disabilities. DRI documents abuses and promotes international awareness and oversight of the rights of people with disabilities. DRI trains and supports disability rights and human rights activists worldwide to promote rights enforcement and service-system reform."

<sup>226</sup> Randal C. Archibold, "Abuses Reported at Mexican Institutions for Disabled," *New York Times*, sec. Americas, November 30, 2010, 2010.

## 4.0. Conclusion

This paper has traced Julio Frenk's career from his student activism on human rights abuses in Mexican psychiatric asylums to his later pursuit of what he called evidence-based policy and advocacy, an approach characterized by statistical rather than documentary-style argumentation. Despite valiant efforts by a dedicated few, Mexico has never achieved the type of mental health reform sought by public health professionals and activists. This fact by itself is not striking, given the failure of countries worldwide to meet their population's mental health needs.<sup>227</sup>

Nevertheless, Mexico's shortcoming in this area remains noteworthy. As an upper-middle-income country with an emerging middle class, involved in a massive overhaul of the health system, more might have been expected. Two broad classes of questions arise: first, what is the relative strategic value of the two advocacy approaches—rights and statistics—described in this narrative; and second, what factors hampered the realization of psychiatric reform.

### 1.4.1. Human Rights and Statistics

Although this narrative followed Frenk as he moved away from rights-based advocacy and toward statistics in the 1980s, human rights never ceased being relevant. Indeed, some of the major victories in Mexican mental health came from the recognition of, and then protection of, the rights of psychiatric patients in hospitals.<sup>228</sup> Rights-based advocacy, particularly exposés of

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<sup>227</sup> Patel, Saraceno and Kleinman, *Beyond Evidence: The Moral Case for International Mental Health*, Vol. 163, 2006), 1312-1315.

asylums, has the advantage of making a visceral impact, which in turn attracts global media attention.<sup>229</sup> Human rights advocacy also has the force of law behind it, at least in theory. In the case of the investigation of the Mexican psychiatric hospitals, MDRI sought to document “violations of the rights of people with disabilities under the new United Nations Convention on the Rights of Persons with Disabilities (CRPD) and other human rights treaties ratified by Mexico.”<sup>230</sup> Rights-based approaches work because they hold countries legally accountable to their own stated commitments.

By contrast, expert-led evaluations, such as the WHO’s 2004 evaluation of the Mexican Mental Health System, have had questionable impact on Mexican policy. In a receptive political climate, quantitative data convince policymakers of the need for action to close the gap between health

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<sup>228</sup> For example, Virginia Gonzalez Torres helped pushed through legislation in 1994 requiring a patient bill of rights to be posted on every floor of psychiatric hospitals.

<sup>229</sup> The reports on Mexican psychiatric abuses conducted by Disability Rights International have garnered the attention of both the *New York Times* and *ABC News Nightline Report*. Archibold, *Abuses Reported at Mexican Institutions for Disabled*, Vol. Americas, 2010).; Alyssa Litoff, "The 'Abandoned' Ones: 'Hell' at Mexican Institution," *ABC News Nightline Report*, sec. Health, November 30, 2010, 2010.

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<sup>230</sup> Eric J. Rosenthal, Erin Jehn and Sofia Galvan, *Abandoned and Disappeared: Mexico's Segregation and Abuse of Children and Adults with Disabilities* (Mexico City, Mexico: Disability Rights International,[2010]).

<sup>230</sup> Ibid.

needs and access (as Frenk argued in 1993).<sup>231</sup> As Part II of this paper has shown, such quantitative evidence has transformed the global perception of mental health from a problem of rich countries to a priority topic for all countries. Yet the Mexican psychiatric establishment did not constitute a receptive audience and, in fact, impeded change.<sup>232</sup> Such resistance to reform should be expected for it requires advocates to transcend the mere marshaling of data. Advocates must find ways to generate political will for reform, especially when faced with long-term societal and governmental neglect.

#### **1.4.2. Mexico's Barriers to Psychiatric Reform**

Disentangling the web of both obstructionist and enabling factors is a task with both historical and policy relevance. Several factors that have hampered psychiatric reform in Mexico could be considered proximate causes, in that they reflect mental health neglect as much as they contribute to it.

Despite the importance of global resolution to prioritize mental health, one of the persistent obstacles to reform in Mexico has been the absence of a grassroots movement for psychiatric reform. While a few patients participated both in the antipsychiatric movement of the 1970s and in Virginia Gonzalez Torres' advocacy work, these movements have been elite-driven, rather

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<sup>231</sup> Julio Frenk, "The New Public Health," *Annual Review of Public Health* 14, no. 1 (1993b), 469-490.

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<sup>232</sup> WHO psychiatrist Benedetto Saraceno reflected that the Mexican psychiatric community was the most hostile and conservative he has ever worked with during his time as the head of the WHO's Department of Mental Health. Interview with Benedetto Saraceno, July 2011.

than bottom-up efforts. Arguably, this has limited the political pressure to change. This absence of a network of mental health stakeholders has been named as one of the key barriers to psychiatric reform in Latin America.<sup>233</sup> In Mexico, this general problem is exacerbated by decades of political suppression and single-party domination that left civil society weakened and without expectations of a responsive government.<sup>234</sup>

Another political impediment to psychiatric reform is the constant need to make tradeoffs between competing priorities. Specifically, Julio Frenk calculated that system-wide health reform needed to precede any single-disease focus. He dedicated his political capital and energy to passing Seguro Popular, a landmark piece of legislation that has transformed access to general health services. Nevertheless, by making this choice, Frenk decided not to devote his time in office to an overhaul of the mental health system. Because Seguro Popular is a health insurance scheme, it has mostly impacted the formerly uninsured in the general population, for example by covering some psychotropic medications, such as antidepressants. It has not directly impacted the disabled and institutionalized patients in asylums, where they remain.

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<sup>233</sup> J. M. Caldas de Almeida, "Mental Health Services Development in Latin America and the Caribbean: Achievements, Barriers and Facilitating Factors," *International Health* 5, no. 1 (March 01, 2013), 15-18.

<sup>234</sup> Shirk, *Mexico's New Politics: The PAN and Democratic Change* (Boulder, Colo.: L. Rienner, 2005), 279.

Another obstacle to mental health has been the resiliency of the biomedical model of mental illness, which in Latin America has translated into an individualistic, apolitical view of psychiatric disorders. As this paper has documented, mental health advocates have made consistent attempts to reframe mental illness as a public problem with social and political roots. Such efforts seem to have yielded only modest success. As a 2005 evaluation of Latin American psychiatry concluded, the shortage of resources for mental health arises from an “excessive dependence on a narrow medical model.”<sup>235</sup>

On this view, a major constraint on psychiatric reform is that the general population in Latin America, not to mention conservative psychiatrists themselves, still considers mental health a matter of, and for, individual medicine rather than public health policy. For example, Mexico’s extreme scarcity of specialists in psychiatry and behavioral health (compared with regional and world averages) is both a problem in itself and a consequence of a prior failure to invest in the education and training of mental health professionals.

Despite the periodic documentation of the horrors of Mexican asylums, the asylum model of psychiatric care, both literally and conceptually, remains entrenched. Several reasons can explain this unhappy continuation. First, the health budget perpetuates the status quo as much as it reflects current priorities. Most of Mexico’s already scarce mental health resources serve the function of constructing and maintaining the physical infrastructure of hospitals and asylums.

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<sup>235</sup> R. Kohn et al., “Mental Disorders in Latin America and the Caribbean: A Public Health Priority,” *Revista Panamericana De Salud Publica = Pan American Journal of Public Health* 18, no. 4-5 (Oct-Nov, 2005), 229-240.

What remains in the budget leaves little room for community mental health programs. Further, as discussed, the public relations boost that politicians gain from opening brand-new buildings has helped keep the hospital-centric system alive.

In addition, the fact that Mexico never underwent a process of psychiatric deinstitutionalization may have contributed to the failure of reform. The general public has never had to confront severe mental illness as a community problem, as has occurred elsewhere. By segregating psychiatric patients out of public view, Mexican asylums silently reinforce the stigma of mental illness.<sup>236</sup> One effect is the lack of political pressure to improve conditions in the asylums. As one asylum caretaker told the MDRI investigators, “there is no political impact for not helping the *abandonados*.”<sup>237</sup> Institutional abuse and neglect of the severely mentally ill appears almost as a wholly separate class of political and social problem than mental health policies for common mental disorders, such as updating insurance coverage for antidepressants.

In combating this dismal scenario, both approaches to Mexican mental health advocacy analyzed in this historical study—rights and statistics—have an important role. Rights-based advocacy’s up-close and personal stories and photographs of severely ill patients languishing in abysmal conditions can provide the emotional drive for reform. By contrast, the apparent impartiality of

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<sup>236</sup> Stigma and discrimination have not been dominant themes in this paper, given the focus on Julio Frenk’s work in antipsychiatry and global health metrics. A full discussion of these issues lies beyond the scope of this paper. Nevertheless, the intangible force of these two factors constitutes one of the most insidious contributors to ongoing political neglect and societal indifference to mental illness.

<sup>237</sup> Archibold, *Abuses Reported at Mexican Institutions for Disabled*, Vol. Americas, 2010).

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statistics offers one way to bypass knee-jerk stigma. By measuring the magnitude of mental illness, population-health summary statistics show its relevance as a critical problem for public policy. The hope for comprehensive psychiatric reform in Mexico ultimately lies in the innovative integration of these two complementary approaches to advocacy.



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## **PAPER 2**

**Beyond Universal Treatment Access:**

**A Multi-Level Study of Availability and Usage of Mental Health Services**

**among HIV+ Individuals in Mexico**



## 2.0. HIV and Mental Illness: A Syndemic Relationship

Individuals living with HIV (human immunodeficiency virus) or AIDS (acquired immune deficiency syndrome) have specific and urgent mental health issues.<sup>1</sup> In fact, HIV and mental illness co-occur in a “syndemic” relationship, defined as one in which the negative effects of each condition adversely impact the other, in this case through poorly understood pathways that are complex, recursive and multidirectional.<sup>2</sup>

Research has shown that prior psychiatric illness not only increases the risk of contracting HIV, but once an individual is infected, also increases the difficulty of managing it.<sup>3</sup> Independent of prior psychiatric illness, both the diagnosis of and living with HIV itself each carries a high psychosocial burden, in reflection of HIV as a chronic, potentially lethal and highly stigmatized disease. This burden of living with HIV can itself worsen an individual’s mental health status. HIV+ individuals have higher-than-average rates of mood/anxiety disorders, substance abuse,<sup>4</sup>

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<sup>1</sup> For an overview of the role of mental health interventions in the global struggle against AIDS, see Francine Cournois, Karen McKinnon and Milton Wainberg, "What can Mental Health Interventions Contribute to the Global Struggle Against HIV/AIDS?" *World Psychiatry* 4, no. 3 (2005), 135.

<sup>2</sup> Michael B Blank et al., "Treatment Considerations for HIV-Infected Individuals with Severe Mental Illness," *Current HIV/AIDS Reports* (10/26, 2013), 1-9.

<sup>3</sup> Cournois, McKinnon, and Wainberg, “What Can Mental Health Interventions Contribute to the Global Struggle against HIV/AIDS?”

<sup>4</sup> HIV+ individuals with co-occurring substance abuse and mental illness have been called “triply diagnosed.” Substance abuse is an independent risk factor for HIV transmission, directly in the case of intravenous drug use, and indirectly in the case of alcohol and other drug use, which can

perceived as well as self-directed stigma and severe psychiatric conditions, such as schizophrenia.<sup>5</sup> More broadly, HIV+ individuals with poor mental health have been found to have worse health outcomes, such as decreased immunological functioning. HIV+ with poor mental health individuals exhibit lower adherence to anti-retroviral medications (ARVs), a problem that can lead to virological resistance and decreased medication efficacy, thus further exacerbating illness.<sup>6</sup>

Socioeconomic stress also accompanies living with HIV and is worse among those who also have mental illness. Those with both HIV and mental illness have greater difficulty in navigating the broader problems, such as poverty, housing, discrimination, un- or underemployment and the financial burden of these health conditions. These broader stresses can then worsen overall health and mental health.<sup>7</sup>

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lead to riskier behaviors that increase risk of transmission. S. L. Ettner et al., "Triply-Diagnosed Patients in the HIV/AIDS Treatment Adherence, Health Outcomes and Cost Study: Patterns of Home Care Use," *AIDS Care* 20, no. 10 (Nov, 2008), 1177-1189.

<sup>5</sup> Sungeun Lee et al., "Use of HIV and Psychotropic Medications among Persons with Serious Mental Illness and HIV/AIDS," *Administration and Policy in Mental Health and Mental Health Services Research* 38, no. 5 (2011), 335-344.

<sup>6</sup> Cournos, McKinnon and Wainberg, *What can Mental Health Interventions Contribute to the Global Struggle Against HIV/AIDS?*, Vol. 4 (Masson, 2005), 135.

<sup>7</sup> According to Calsyn et al, psychological barriers to seeking mental health care, such as "vacillating motivation," also inhibit adequate treatment. For a discussion of specific recruitment and retainment strategies for individuals with both HIV and co-occurring substance abuse and mental illness, see R. J. Calsyn et al., "Recruitment, Engagement, and Retention of People Living

Because of these varied pathways in which mental illness and HIV impact the effect of each other, mental health support is a critical component of comprehensive HIV care. Tackling mental health needs has been shown to help infected individuals to manage life with HIV. Once their mental health needs are treated, HIV+ individuals do not show worse health outcomes or ARV adherence than HIV+ patients without mental illness.<sup>8</sup> However, one study found that HIV+ individuals with mental illness or substance use disorders did exhibit lower adherence to psychotropic medications.<sup>9</sup>

### **2.0.1 What factors affect usage of mental health services among HIV+ patients in Mexico?**

Mexico provides a good case study for exploring the use and availability of mental health services for HIV+ patients. Since the early 2000s, Mexico's AIDS program has provided free antiretroviral treatment to HIV+ citizens and has achieved a high coverage rate (over 80% in 2012).<sup>10</sup> In 2008, one study found that Mexico spends more on treatment and care per person living with HIV (PLWHIV) than any other Latin American country.<sup>11</sup>

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with HIV and Co-Occurring Mental Health and Substance use Disorders," *AIDS Care* 16 Suppl 1 (2004), S56-70.

<sup>8</sup> Sungeun Lee et al, "Use of HIV and Psychotropic Medications among Persons with Serious Mental Illness and HIV/AIDS."

<sup>9</sup> Ibid Lee et al., *Use of HIV and Psychotropic Medications among Persons with Serious Mental Illness and HIV/AIDS*, Vol. 38 Springer, 2011), 335-344.

<sup>10</sup> According to UNAIDS data, Mexico is one of 12 lower- and middle-income countries (LAMICs) to achieve at least 80% coverage of ARVs of those HIV patients who need it. See World Health Organization, UNICEF, and UNAIDS, "Global Update on HIV Treatment 2013:

The prevalence rate of HIV has remained very low (i.e., lower than its northern neighbor, the United States, or to its south, Honduras).<sup>12</sup> Mexico's success at containing the epidemic has been attributed to both the Ministry of Health's decisive action to shut down its commercial blood market in the early 1980s and the fact that Mexico's HIV epidemic has remained "nuclear," that is, concentrated among men who have sex with men (MSM) in urban areas.<sup>13</sup>

In contrast with its robust national HIV program, Mexico stands out as a country with a particularly inadequate mental health system. To be sure, access to mental health care is a global problem,<sup>14</sup> and the gap between need and access to mental health care tends to be particularly

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Results, Impact, and Opportunities," Geneva, Switzerland: World Health Organization, 2013, p. 37.

<sup>11</sup> Daniel Arán-Matero et al., "Levels of Spending and Resource Allocation to HIV Programs and Services in Latin America and the Caribbean," *PloS One* 6, no. 7 (2011), e22373.

<sup>12</sup> Vikram Patel et al., "Treatment and Prevention of Mental Disorders in Low-Income and Middle-Income Countries," *The Lancet* 370, no. 9591 (, 991-1005).

<sup>13</sup> For more on the concentrated MSM HIV epidemic, see Sergio Bautista-Arredondo et al., "Is the HIV Epidemic Stable among MSM in Mexico? HIV Prevalence and Risk Behavior Results from a Nationally Representative Survey among Men Who have Sex with Men," *PloS One* 8, no. 9 (2013), e72616.; Carlos del Rio and Jaime Sepúlveda, "AIDS in Mexico: Lessons Learned and Implications for Developing Countries," *AIDS* 16, no. 11 (2002).

<sup>14</sup> Denise Razzouk et al., "Scarcity and Inequity of Mental Health Research Resources in Low-and-Middle Income Countries: A Global Survey," *Health Policy* 94, no. 3 (3, 2010), 211-220.

acute in low- and middle-income countries.<sup>15</sup> In addition, some studies have suggested that the Mexican population may have a lower need for mental health services because of a lower prevalence of mental health disorders. For example, one study found that Mexico has a lower prevalence of depression and anxiety than the United States, Europe and Brazil.<sup>16</sup> Another study of depression among women with HIV in the Mexican state of Oaxaca showed that they exhibit both lower than average levels of depression and mental health service usage.<sup>17</sup>

However, lower need alone does not explain the observed low rate of mental health service usage in Mexico. According to one study, those Mexicans who do need mental health care based on diagnosis have very low levels of service use.<sup>18</sup> This same study found that less than 20% of Mexicans with mood disorders sought any help at all; for those individuals who did access mental health care, only 50% received minimally adequate treatment within a specified time

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<sup>15</sup> Patel et al, "Treatment and Prevention of Mental Disorders in Low-Income and Middle-Income Countries."

<sup>16</sup> Overall, Mexicans had a 9.2% rate of depression at some point in their lifetime, with 4.8% experiencing depression in last 12 months. This prevalence is much lower than in the United States, Europe or Brazil, where on average more than 15% of the population has a major episode in their lifetime, and more than 6% in the last 12 months. Shoshana Berenzon et al., "Depresión: Estado Del Conocimiento Y La Necesidad De Políticas Públicas Y Planes De Acción En México," *Salud Pública De México* 55, no. 1 (2013), 74-80.

<sup>17</sup> Richard L. Sowell et al, "Depression in HIV-Infected Oaxacan Women: Implications for Mental Health Services." *Online Journal of Medicine and Medical Science Research* 2, no. 1 (2013).

<sup>18</sup> Shoshana Berenzon et al., "Depresión: Estado Del Conocimiento Y La Necesidad De Políticas Públicas Y Planes De Acción En México," *Salud Pública De México* 55, no. 1 (2013), 74-80.

frame. These low rates make Mexico one of the countries with the greatest delays both in seeking and receiving mental health care in the world.<sup>19</sup> One plausible reason for this low rate of service usage may be low numbers of mental health professionals in Mexico: 2009 OECD data shows that Mexico was absolute last among countries in terms of number of psychiatrists per 100K population.<sup>20</sup>

The contrast between Mexico's generous and successful HIV program and its generally inadequate mental health system raises the question of how the mental health needs of Mexico's HIV+ population are met. No studies to date have examined this issue. In the country as a whole, great inequalities in wealth and access to health care exist. However, the fact that the Mexican HIV program offers free services with minimum standards of care set by the federal AIDS agency suggests that all HIV+ individuals in Mexico should have similar access to the basic services guaranteed by the clinics. Neither the availability of mental health services nor their patterns of usage within Mexico's HIV clinics has been measured to date.<sup>21</sup>

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<sup>19</sup> Ma Elena Medina-Mora et al., "Resultados De La Encuesta Nacional De Epidemiología Psiquiátrica En México," *Salud Mental* 26, no. 4 (2003), 1.

<sup>20</sup> For example, in 2009, Mexico had 0.9 psychiatrists per 100K population versus the OECD's average of 15.4 per 100K. By contrast, the top country, Switzerland reports 42.2 psychiatrists per 100K population. Organisation for Economic Co-operation and Development, "Health Data 2011," <http://bit.ly/Pji2v8>.

<sup>21</sup> Reflecting the general lack of attention on the mental health aspects of HIV in Mexico, when asked, none of the HIV or mental health interviewees could think of any study or program on any relationship between HIV and mental health. Similarly, when I tried to search for such a study in the *Mexican Journal of Public Health*, searches for combinations of key Spanish terms for mental health and HIV (e.g., "salud mental," "VIH," "SIDA," "enfermedad mental," "VIH") turned up zero responses, as of July 2013.

Even if the same level of mental health services were available across clinics, other factors may influence which HIV+ individuals actually access mental health care as part of their HIV care. This study examines which factors are associated with whether or not HIV+ patients attending Mexican HIV clinics receive mental health services.

To answer this question, this study adapts the Andersen Behavioral Model of Health Care as a theoretical framework. According to this model, both patient-level factors and clinic-level factors may influence the outcome (see Figure 1).<sup>22</sup> First, patient-level factors, such as mental health need, stress level, alcohol use, gender, age or education may influence whether or not patients seek and/or receive mental health care.<sup>23</sup> Secondly, factors specific to the HIV clinics may also matter a great deal to the outcome. Clinic-level factors that may influence patterns of mental health service usage include: the level of general medical human resources available to patients, the level of mental health staffing (psychologists, psychiatrists, social workers), the procedures

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<sup>22</sup> Andersen also discusses the importance of environmental factors, but in this study all patients would share environmental factors, such as national context, access to the HIV program and cultural forces. Because they do not differ on those factors, this study omits environmental factors from the analysis. For more on the Andersen Behavioral Model of Health Care and its applications to low- and middle-income countries, see R. M. Andersen, "Revisiting the Behavioral Model and Access to Medical Care: Does it Matter?" *Journal of Health and Social Behavior* 36, no. 1 (Mar, 1995), 1-10.; R. M. Andersen et al., "Access to Medical Care for Low-Income Persons: How do Communities make a Difference?" *Medical Care Research and Review* : *MCRR* 59, no. 4 (Dec, 2002), 384-411.; E. H. Bradley et al., "Expanding the Andersen Model: The Role of Psychosocial Factors in Long-Term Care Use," *Health Services Research* 37, no. 5 (Oct, 2002), 1221-1242.

<sup>23</sup> Psychosocial factors also influence seeking care, although not emphasized in the original Andersen Model. For a discussion of the role of psychosocial factors in long-term care decisions, see Bradley et al, "Expanding the Andersen Model."

for psychological screening, the presence of patient-led support groups, the training of non-specialty staff (nurses, physicians) in providing counseling, the patient/provider ratio, the staff's effectiveness in referring patients to outside psychiatric care and the availability of psychiatric care in the community.



Figure 1: Two potential pathways between patient- and clinic-level variables and receiving mental health care in Mexican HIV clinics, based on the Andersen Behavioral Model of Health Care.

Given the theoretical background of the Andersen Model, this study looks at whether these broad categories of patient- or clinic-level factors are associated with patients receiving mental health care in the HIV clinics. In other words, can we detect differences between those patients who receive mental health care and those who do not, whether in terms of mental health status, socioeconomic issues, or the clinics they attend? To answer this main question, this paper necessarily examines a second research question regarding the availability of mental health resources in and between Mexican HIV clinics.



## 2.1 Methods

In order to answer the research questions, this paper analyzes data from the first nationally representative survey of the HIV response in Mexico. Specifically, this study uses data gathered by CISIDAT, a Mexican research consortium dedicated to research HIV and TB in Mexico.<sup>24</sup> The data derives from the first sub-project, “Treatment for People Living with HIV/AIDS and Prevention of Secondary Cases: Evaluation of the Response of the Mexican Health Sector,” of the larger CISIDAT project.<sup>25</sup>

## 2.2. Design and Size of the Sample

This study’s sample comprises two hierarchically related levels of data: HIV/AIDS patients, nested in clinics. The survey researchers’ sampling technique accounted for this hierarchical relationship. First, a sample of 53 facilities was selected that represents a comprehensive list of services of care and treatment for patients living with HIV and AIDS in Mexico. This sample was stratified according to type of clinic (e.g., Social Security, Private, Hospital and Ministry of

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<sup>24</sup> The Consortium of Research in HIV/AIDS/TB (*Consortio de Investigación sobre VIH/SIDA/TB*, or CISIDAT) has as its mission to increase investigation into HIV/AIDS and TB in Mexico.

<sup>25</sup> The sub-project’s name in Spanish is “Tratamiento para personas viviendo con VIH y SIDA y prevención de casos secundarios: una evaluación de la respuesta del sector salud mexicano.” The larger project is CISIDAT’s evaluation of HIV in Mexico, called “Integrated Research of the Management and Treatment of HIV/AIDS and Co-infection with Tuberculosis in Mexico: A Multidisciplinary and Inter-institutional Approach,” or, in Spanish: “Investigación integral de manejo y tratamiento del VIH/SIDA y su coinfección con tuberculosis en México: Un enfoque multidisciplinario e interinstitucional.”

Health).<sup>26</sup> The probability of selection was proportional to the number of patients under antiretroviral treatment in each unit. The information for the definition of the sampling frame comes from the national registry of AIDS cases at the Secretary of Health, with additional data from the social security organizations and the private sector.<sup>27</sup>

Second, a random sample of patients was selected from the random sample of care centers. At each site, all physicians in the care centers who treated patients with HIV/AIDS were interviewed.<sup>28</sup> Then, a random sample of patients was selected that aimed to be representative of all those taking ARVs under each treating physician. The goal was to sample approximately 25% of total active patients in the CISIDAT dataset.

This study used the patient and clinic surveys from the larger subset. After removing five clinics that had incomplete data, the final sample size was 2,678 patients, nested in 48 clinics.<sup>29</sup>

## **2.2.2. Variables**

### *2.2.2.a. Outcome Measure*

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<sup>26</sup> The subsystems of clinics are the health services of Mexican state ministries of health and the National Secretary of Health, services of the national social security organizations (IMSS and ISSSTE) and, to the extent possible, of the private sector.

<sup>27</sup> The sample was drawn from the complete CISIDAT dataset, which contains information for approximately 1,330 clinics (19,188 patients). There is complete information for 611 clinics (46% of the total) in which 12,761 patients were reported (67% of the total). Each clinic has information about name, institution, number of reported patients, city, county, and state.

<sup>28</sup> The survey of the treating physicians generated a separate sample, which is not included in this study.

<sup>29</sup> The researchers surpassed their minimum number of 1,875 patients needed to have enough power to test hypotheses (with 95% certainty) in events with a prevalence of 5%, assuming a correlation of 0.013.

The outcome variable is whether or not the patient had received “psychological support from a specialist in their last visit to the clinic.” It is a dichotomous variable that was constructed as a composite of two survey questions. The first question asked the patient whether they had *sought and/or received* psychological support from the specialist in the last visit [emphasis added]. This ambiguous wording made it difficult to discern from this paper alone whether a patient had either sought but not received mental health care or had both sought and received psychological support. Therefore, I added the next survey question, which asked “If yes, how long did the session of psychological support last?” Here patients had to enter a length of time. I classified a patient as having received psychological support if they answered yes to the first question and provided a positive length of time on the second question.

#### *2.2.2.b. Individual-Level Predictors*

*Mental Health Predictors:* The three individual-level mental health predictors are depression level, stress level and alcohol use. First, “depression level” is a continuous, composite variable that is the sum of each respondent’s self-reported responses to five survey questions about mood and mood-related functioning in the last week. For ease of interpretation, I compressed the original scale of [5-25] to [0-1].<sup>30</sup> Second, “stress level” is a continuous, composite variable that represents the sum of each respondent’s self-reported responses to nine survey questions about perceived stress and worry in the last week. For ease of interpretation, I compressed the original scale of [9-45] to [0-1].

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<sup>30</sup> Dulce Alejandra Balandran Duarte, "La Calidad Interpersonal En La Atencion De Pacientes Con VIH Y Su Relacion Con La Adherencia Al Tratamiento Antiretroviral--Evaluacion En Centros Ambulatorios Para La Prevencion Y Atencion Del SIDA Y ITS--Mexico 2008" (Unpublished Master's Thesis, Instituto Nacional de Salud Publica), 1-72.

Third, “drank last week” is a dummy variable that reflects whether or not the patient reported drinking alcohol at all in the last week (0 if no and 1 if yes). Alcohol use is counterindicated among those with HIV, particularly those who are taking ARVs.<sup>31</sup> In addition, the prevalence of alcohol use disorders is high in the Mexican general population.<sup>32</sup> Since a small percentage of patients reported drinking at all and a very small number reported drinking more than one day per week or more than 1-2 drinks per day, making fine-grained distinctions between alcohol use and other outcomes was difficult. Compressing these responses into a dichotomous dummy variable made analysis easier.

*Socioeconomic Predictors:* In addition to mental health variables, other individual-level predictors include socioeconomic factors that may influence whether or not patients receive mental health care. The other patient-level variables included in the models were female, age (centered on mean age of 38.2), heterosexual, education level beyond a secondary degree, being employed in the last week and whether insured or not.

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<sup>31</sup> Laurent Michel et al., "Harmful Alcohol Consumption and Patterns of Substance use in HIV-Infected Patients Receiving Antiretrovirals (ANRS-EN12-VESPA Study): Relevance for Clinical Management and Intervention," *AIDS Care* 22, no. 9 (2010), 1136-1145.

<sup>32</sup> M. E. Medina-Mora, "Mexicans and Alcohol: Patterns, Problems and Policies," *Addiction (Abingdon, England)* 102, no. 7 (Jul, 2007), 1041-1045.

### *2.2.2.c. Clinic-Level Predictors*

In contrast to the patient-level variables, which derive from the patient survey, the clinic-level predictors contain responses from the second survey in the sample, which was answered by clinic administrators. The clinic-level predictors include: percentage of patients reporting mental health care, percentage of females, size (number of patients per clinic), mental health staffing (number of psychologists, psychiatrists and social workers), days per week and hours per working day that each category of mental health staff devotes to HIV+ care, the number of full-time equivalent psychologists per clinic, whether or not the clinic offers psychological support and counseling, and if so, which provider in the clinic provides the counseling (e.g., doctor, psychologist, psychiatrist, nurse, etc.).

## **2.3. Results**

### **Descriptive Statistics of Patients**

The descriptive statistics show that 21% of patients reported that they had received counseling or mental health care from a specialist across the last three visits to the clinic. In terms of the outcome variable, women were 10% more likely than men to report having received psychological support (28% of women vs. 18% of men).

The descriptive statistics showed other important differences between men and women in the sample. The sample is 76% male (n=2,061) and 23% female (n=617), a ratio of roughly 3 to 1. Despite this imbalance, this ratio actually over-represents women compared with the Mexican

HIV+ population, which has a male-female ratio of approximately 6 to 1.<sup>33</sup> Women's mental health seems to be worse: women were 7% more likely than men to report having been depressed in the last week (35% vs. 28%), and they were also 19% more likely than men to report having drunk alcohol in the last week (75% vs. 56%). Both differences are statistically significant at  $\alpha=0.01$  level. Both men and women reported feeling stressed 52% of the time. 98% of the surveyed respondents, either male or female, had taken ARV medication in the last three months.

In terms of the sociodemographic characteristics, some notable differences between male and female samples arose. Men and women in the sample have the same mean age (38). Compared with women, men were more homosexual, more single (than married), less likely to be divorced (perhaps due to never having married), more employed and less likely to be searching for work, more likely to have health insurance, and less likely to report having received no education at all, in greater possession of bachelor's, master's and PhD degrees but fewer professional degrees. The results of the descriptive statistics are shown in Table 2.1.

*Table 2.1 Patient Characteristics, by Sex (N=2,678)*

Variable, by category	Sample Means	Male Means	Female Means
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<sup>33</sup> CENSIDA is Mexico's national AIDS agency: Centro Nacional de la Prevención y el Control de VIH/SIDA, or in English, the National Center for the Prevention and Control of HIV/AIDS. For the 2012 data on the HIV epidemic in the control, see Centro Nacional de la Prevención y el Control de VIH/SIDA, "VIH/SIDA en México 2012," Mexico City: CENSIDA, 2012.

# Patients	2,678	2,061	617
% Total Sample	100	76	23
<hr/>			
Mental and General Health	All Responses in %		
Psych support last visit? (%Yes)	21	18	28***
	(0.4)	(0.4)	(0.4)
Depressed, how often last week? (0-100%)	29	28	35***
	(0.2)	(0.2)	(0.2)
Stressed, how often last week? (0-100%)	52	52	52
	(0.1)	(0.1)	(0.1)
Alcohol in last week? (% Yes)	61	56	75***
	(0.5)	(0.5)	(0.4)
ARVs last 3 months? (% Yes)	98	98	98
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Sociodemographics	All Responses in %		
Age (mean years)	38.2	38.3	38
	(10.2)	(9.7)	(11.5)
Sexual Orientation (% responses)			
<i>Heterosexual</i>	49	35	96
<i>Homosexual</i>	34	44	18
<i>Bisexual</i>	8	10	2
<i>Other/Not Specified</i>	9	11	0
Insured? (% Yes)	72	73	67***
Marital Status (% selected responses)			
<i>Single</i>	59	70	22
<i>Married</i>	16	13	24
<i>Unmarried Partnership</i>	13	1	2
<i>Divorced</i>	19	17	28
Education (% selected responses)			
<i>None</i>	4	3	8
<i>Secondary</i>	3	1	3
<i>Bachelors</i>	21	23	11
<i>Technical/vocational school</i>	8	8	7
<i>Professional Degree</i>	25	5	20
<i>Masters/Doctorate</i>	2	2	0
Employed in Last Week? (% selected responses)			
<i>Employed</i>	65	72	44
<i>Student</i>	2	2	1
<i>Did not work</i>	13	12	16
<i>Homemaker</i>	9	3	32
<i>Seeking Work</i>	4	5	1
<hr/>			
Note: *** p<0.01, ** p<0.05, * p<0.1			
Standard deviations in parentheses			
<hr/>			

### **2.3.2. Results of Random and Fixed Effects Models**

To more fully examine the relative association of patient- and clinic-level traits with receiving psychological support, I fitted two multi-level multivariate linear regression models that each tested the association between mental health-related factors (depression and stress level and alcohol use) and relevant demographic characteristics (e.g., age, sex, insurance status, employment status, education level and sexual orientation) on whether or not patients attending the HIV clinics reported receiving mental health care during at least one of their last three visits.

First, a random effects model used individual-level predictors to examine their association with the outcome. Those with the most severe depression were 5.8% more likely to report having received mental health care than those who were not at all depressed ( $p=0.82$ ). This result was significant at  $\alpha=0.01$  level. Second, patients who reported feeling stress all the time in the last week had a 3% greater probability of receiving mental health care, though this result was not significant. The third mental health predictor, whether or not the patient drank last week, had no association with the outcome. Females were 5% less likely to receive mental health care than men, a result significant at  $\alpha=0.05$  level. None of the remaining sociodemographic or interaction predictors had significant associations with the outcome.

In addition to the fact that the patient-level characteristics did not have a strong association with the outcome, the random effects model had a large standard deviation (24.6%). Both of these findings indicated that the patient-level predictors were not explaining much of the observed variation between the clinics in terms of percentage of patients who received mental health care. The results of the random effects models are shown in column 1 of Table 2.2.



Building on the results of the random effects model, I sought to further explore the role of clinics. To do so, I now conducted a fixed-effects model that included the same patient-level predictors, but also added dummy variables for each of the 48 clinics. Treating clinics as a fixed effect by using dummy variables allowed the examination of the association of the individual-level predictors on the outcome, controlling for any between-clinic variations. In both models, I also tested interactions between key variables, none of which were significant. The results of the fixed effects model are generally similar to the random effects model. In addition, several of the clinics have outcomes that are significantly different from the reference clinic, which underscores that the clinic variation is considerable. The results of the fixed effects model are shown in column 2 of Table 2.2.

Taken together, the results of both models lend credibility to the idea that which clinic a patient attends might better predict whether or not they receive mental health care perhaps better than individual characteristics. Yet, uncertainty remains about which specific clinic characteristics may distinguish high- and low-performing clinics.

Table 2.2. Results of Random Effects and Fixed Effects Models  
(Patients N=2,277; Clinics N=48)

Patient-Level Variables	RE Model	FE Model
	All Results in %	
<i>Depressed in Last Week (% Always)</i>	5.6 (0.10)	5.8* (0.08)
<i>Stressed in Last Week (% Always)</i>	3.0 (0.7)	3.4 (0.7)
<i>Drank in Last Week (% Yes)</i>	0.3 (0.8)	0 (0.8)
<i>Female</i>	-4.7 (0.4)	0 (0.0)
<i>Age</i>	0 (0.5)	0 (0.6)
<i>Heterosexual</i>	0 (0.8)	0 (1.0)
<i>Employed</i>	-2.0 (0.3)	0 (0.3)
<i>Insured</i>	0 (0.9)	0.6 (0.6)
<i>Education beyond Secondary</i>	0 (0.9)	0 (0.9)
<i>Age_cent2</i>	0 (0.5)	0 (0.5)
<i>FemaleXage_cent</i>	0 (0.6)	0 (0.5)
<i>FemaleXage_cent2</i>	0 (0.2)	0 (0.3)
<i>RE Parameter Estimate</i>	24.6	N/A
<i>Standard Error</i>	(0)	N/A
Note: *** p<0.01, ** p<0.05, * p<0.1		
P-values in parentheses		

### 2.3.3. Clinic Characteristics, by Outcome

To try to disentangle which specific features of clinics matter in patients receiving psychological support, I conducted a descriptive comparison of clinic characteristics within the 48 sampled clinics. I compared the clinics across four categories: the total sample of clinics (in which on average 21% of patients reported that they received mental health care), the single Mexico City HIV clinic (where 6% of patients reported that they received mental health care), and the top and bottom five clinics in terms of the percentage of patients receiving psychological support (79% vs. 0%). I also compared these four categories of clinics on basic features relevant to mental health care (e.g., number of full-time equivalent psychologists, number of overall mental health staff, size of the clinic and percentage of female patients). The results of the clinic descriptive statistics are shown in Table 2.3.

In the top five clinics, on average, 79% of patients received mental health care. In addition, the top five clinics all had positive response rates above 68%, with the best clinic reporting 90%. By contrast, in the bottom five clinics, none of the patients reported receiving psychological support in their last clinic visit.

The results of this descriptive analysis of clinics reveal that the top five and bottom five performing clinics do not appear different from the average clinic on basic characteristics such as patient population or clinic size.<sup>34</sup> The number of full-time equivalent psychologists (FTE) was higher in the top five clinics than in the bottom five (0.9 in top clinics vs. 0.1 in bottom clinics).

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<sup>34</sup> Since Mexico City's Clinica Condesa appeared similar to other clinics on all measures except size (n=318 versus the sample mean of 49), the table shows median size for the clinics rather than mean. A separate column for Mexico City is also included.

The top and bottom clinics differed in another respect. Virtually all clinics reported that they offered counseling and psychological support. When then asked which provider offers that support, the clinics provided very different answers. Across all clinics, the psychologist (47%) and the physician (41%) were given as the top two responses as to the type of professional who gives counseling. By contrast, among the top five clinics, 100% of administrators reported that the psychologist gives the counseling. Among the bottom five clinics, the pattern of responses was quite different, with 0% reporting the psychologist gives the counseling, but with 40% reporting the treating physician provides counseling and 23% saying that the social worker does. Worth mentioning is the fact that no clinic in the entire sample mentioned a psychiatrist or nurse as the provider who gives counseling.<sup>35</sup>

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<sup>35</sup> The failure to mention a psychiatrist is not an astonishing result, given their likelihood of providing medication consultation rather than therapy. However, the absence of nurses seems surprising, given the informal counseling that nurses are likely to perform. However, the survey question did not offer psychiatrists as a given response, although clinic administrators had the option of specifying a professional not mentioned in the survey list.

Table 2.3. HIV Clinic Characteristics, by Mexico City, Top 5 and Bottom 5 Clinics in terms of Percentage of Patients Receiving Psychological Care (N=48)

Basic Clinic Characteristics	All Clinics	Mexico City (counts)	Top 5 Means	Bottom 5 Means
<i>Total No. of Patients</i>	2,678	318	185	239
<i>Received Psych. Care (% Y)</i>	21	6	79	0
<i>Age (mean yrs.)</i>	38	36	36	41
<i>Female (%)</i>	22	8	31	24
<i>Clinic Size (mean patients/clinic)</i>	50	318	50	49
Mental Health Staffing per Clinic (Part or Full Time)				
<i>No. of Psychologists</i>	2	4	1	2
<i>No. of Psychiatrists</i>	1	1	0	3
<i>No. of Social Workers</i>	10	5	0	23
Psychologists for HIV Care/Clinic				
<i>No. of days/week Psych. on HIV (mean)</i>	4	5	5	2
<i>No. of hours/day Psych. on HIV (mean)</i>	5	7	11	1
<i>No. of FTE Psych. on HIV Care</i>	1.1	0.7	0.9	0.1
Mental Health Services in Clinic				
<i>Clinic provides psych./counseling? (% Yes)</i>	98	Yes	100	100
<i>Who offers psych/counsel? (% responses)</i>				
Psychologist	47	—	100	0
Doctor	41	Yes	0	40
Social Worker	4	—	0	23

## **2.4. Discussion and Policy Recommendations**

This study represents the first examination of the availability and usage of mental health services in Mexico's national HIV program. As such, the study's findings have important policy implications, both for Mexico and internationally. Despite the importance of mental health care for HIV+ individuals and the prominence of the Mexican HIV program, the availability and usage patterns of mental health care among HIV+ patients in the Mexican HIV response has not previously been studied. Thus, this study contributes to the active research program in Mexico pursued by the CISIDAT and others to evaluate both the national HIV response and the international effort to better understand the relationship between HIV and mental health.

Two related concerns arise from the fact that only 21% of HIV+ patients on average report receiving mental health care. In light of Mexico's stated commitment to psychological care for HIV+ patients, this figure seems low. Mexican clinical guidelines call for all centers caring for HIV+ patients to have a psychology department, on the grounds that the HIV+ population has mental health needs greater than the average population. Thus, we need to better understand the reasons behind the overall relatively low rate of HIV+ patients receiving mental health care services. Secondly, we should take a higher-level perspective and ask whether or not receiving psychological care from a specialist should be the focus of improving mental health care in HIV clinics.

Regarding explanations for the low rates of reported psychological care for HIV+ patients, one hypothesis might be that the patterns of mental health service and seeking usage among the HIV+ sub-population simply reflect the very low levels of HIV in the average Mexican

population. Indeed Mexico has a rate of mental health service utilization that is low even compared with poorer countries in the region.<sup>36</sup> However, because of the expansive coverage offered by the Mexican national AIDS program, the HIV+ population may have access to a wider range of services than the average Mexican. If the national hypothesis were true, there should be a relatively consistent percentage of patients reporting mental health care across the clinics, even if low. Yet, wide variations in the average rates of reported mental health service usage appeared across all 48 clinics.

A second plausible explanation for the reported low overall rate of mental health care usage is historical. Mexico's HIV clinics began in the 1980s as voluntary counseling and testing centers. Even after effective medications for HIV have become available, some have suggested that clinics have maintained this narrow focus on initial testing and distribution of anti-retroviral medication.<sup>37</sup> The clinics are not designed, nor claim to provide comprehensive services for all health needs of HIV+ patients. (For instance, they do not provide treatment for all opportunistic infections.)<sup>38</sup> On that understanding, the principal role of the psychologist or other mental health

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<sup>36</sup> G. Borges et al., "Treatment and Adequacy of Treatment of Mental Disorders among Respondents to the Mexico National Comorbidity Survey," *The American Journal of Psychiatry* 163, no. 8 (Aug, 2006), 1371-1378.

<sup>37</sup> Interviews with Carlos Magis-Rodriguez, Carlos del Rio, Jorge Saavedra, and Jaime Sepúlveda, July 2010; and Lucila Villegas Icazbalceta, July 2013.

<sup>38</sup> Interview with Julio Frenk, Mexico City, July 2010.

provider in Mexican HIV clinics is to provide counseling around the initial HIV diagnosis, not to provide ongoing therapeutic support.<sup>39</sup>

A third explanation for the low rate may be that some HIV patients access mental health care elsewhere, a result this survey would not detect. Indeed, if a provider in an HIV clinic determines that a patient has a need for additional mental health care, the patient can be referred to another facility equipped to provide such care.<sup>40</sup> Even if patients do not turn to another mental health provider for support, they may seek counsel with other trusted individuals. One study has shown that when faced with problems, Mexicans tend to speak with a minister or someone at their church, or with their family or friends.<sup>41</sup> In addition, the fact that insured patients receive reportedly lower rates of mental health care than non-insured patients may reflect that those with insurance have additional options to seek mental health care if necessary.

From a clinical standpoint, patients should receive psychological care based on their mental health status rather than clinically irrelevant factors, such as education or employment status. (Among HIV+ individuals, a more expansive notion of need prevails: given the high psychosocial burden of living with the disease, psychological support should be available to all.) Severe depression has a small association with receiving mental health care, which indicates that the HIV clinics may be at least detecting and acting upon depression in some cases. On the other

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<sup>39</sup> Interview with Lucila Villegas Icazbalceta, July 2013.

<sup>40</sup> Ibid.

<sup>41</sup> Guilherme Borges et al., "Delay of First Treatment of Mental and Substance use Disorders in Mexico," *Journal Information* 97, no. 9 (2007).



hand, the fact that the most depressed have only a 6% higher probability of receiving care than those who are not at all depressed suggests that patients with mild or moderate depression may not be detected and/or not be receiving beneficial psychological support or counseling.

Men and women differed on several factors, both in terms of percentage receiving mental health care (women report higher rates than men) and in terms of their mental health status and socioeconomic status (women seem to do worse on these metrics). Taken at face value, these findings suggest that women's higher percentage of receiving mental health care may be driven by both their measurably lower mental health status and by their worse status on important measures of social and economic well-being. If gender-specific differences in true mental health need explain the higher percentage of women receiving mental health care, then this result would be clinically appropriate. Yet there is some reason to doubt this explanation.

The observed differences in receiving mental health care may reflect differences in socioeconomic, clinically irrelevant factors between men and women. First, women's poorer mental health status may be related to their worse socioeconomic status. Secondly, women may be more open to reporting their behavior (e.g., they report higher rates of drinking), and be more willing to seek (and admit to seeking) mental health care than men. Further, the demonstrated tendency of providers to recommend mental health care more often for women than men, all other things being equal, may play a role.<sup>42</sup>

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<sup>42</sup> Soraya Seedat et al., "Cross-National Associations between Gender and Mental Disorders in the WHO World Mental Health Surveys," *Archives of General Psychiatry* 66, no. 7 (2009), 785.

Moving from patients to clinic-level descriptive statistics, one notable result was the difference between which categories of providers give counseling to patients. Since the treating physician and the social worker were the top two responses across all clinics, this result might be viewed as a positive finding consistent with global policy recommendations. Indeed, global mental health research and policy initiatives have promoted the integration of mental health care within primary care as a means to expand access, rather than restricting to specialists such as psychologists or psychiatrists.<sup>43</sup> Since the top five clinics have more FTE psychologists than the bottom five clinics, this raises the question of whether the presence of more psychologists increases both real access to counseling and patients' perceptions and recollection of receiving mental health care.<sup>44</sup>

More generally, the observed differences between clinics on the outcome variable are probably not fully explained by tangible metrics such as those in the survey, but rather by latent predictors. (The large residual in the random effects model underscores this idea.) The clinic's culture, atmosphere and practice patterns most likely have a large effect on whether or not a patient seeks

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<sup>43</sup> For example, see Vikram Patel and Betty Kirkwood, "Perinatal Depression Treated by Community Health Workers," *The Lancet* 372, no. 9642 (, 868-869.

See also Benedetto Saraceno et al., "Barriers to Improvement of Mental Health Services in Low-Income and Middle-Income Countries," *The Lancet* 370, no. 9593 (, 1164-1174.

<sup>44</sup> This divergence in responses between top and bottom clinics might also reflect the discrepancy between the outcome variable, which asks whether a patient has received psychologist support from a specialist, and this clinic-level variable, which asks the clinic administrator who provides counseling in the clinic. These two variables should be measuring two different things: specialized mental health care vs. general counseling that a physician could do well. It seems unlikely, however, that the top five clinics all misunderstood the question and incorrectly reported psychologist as the sole provider of counseling.

or receives mental health care.<sup>45</sup> Indeed, a range of sources have suggested that there is a pervasive culture of disrespect, along with homophobia on the part of clinic staff, toward HIV+ patients.<sup>46</sup> As further confirmation of this general idea, many patients in this study offered disparaging comments in the open response portion of the survey that described being disrespected by the staff, treated as less than human, or unable to get psychological support. In a paradoxical confirmation of the stigma attached to mental health care, one respondent became offended by even being asked about receiving psychological support, indicating the high level of stigma it carries even among those with HIV, a highly stigmatized primary diagnosis.

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<sup>45</sup> Judith K. Bass, Paul A. Bolton and Laura K. Murray, "Do Not Forget Culture when Studying Mental Health," *The Lancet* 370, no. 9591 (, 918-919).

<sup>46</sup> In response to the high number of protests about staff homophobia toward patients in HIV clinics, the Secretary of Health began an outreach campaign called "A Homophobia Free Zone." Primary sources provided during interview with Carlos Magis Rodriguez, July 2010.

### 2.4.1. Limitations

The study has certain limitations. First, as a cross-sectional study, no causal relationship between the predictor and outcome variables can be determined. Given that the ideal outcome is that patients with a specific mental health need would be detected in the clinical encounter and provided with treatment, the cross-sectional design serves well. Second, the ambiguity in the phrasing of the survey questions for patients about psychological care may undermine the validity of the outcome variable (as discussed above).<sup>47</sup> Third, response bias may mean that some patients are underreporting their depression or alcohol use.

Although the descriptive summary statistics of the patient sample should be generalizable to the larger sample of patients in the CISIDAT database, they may not be generalizable to the Mexican HIV+ population as a whole. HIV+ patients who attend the type of clinics sampled in the survey principally do so either to get tested for HIV or to receive antiretroviral medications (ARVs) (as reflected by the 98% of respondents who reported receiving them). In addition, the researchers specifically sought out patients on ARVs in order to investigate the patterns of management and usage. These sampling issues make it plausible that the study sample is sicker than the general HIV+ population (many of whom do not need ARVs), and their mental health needs may be different as well.<sup>48</sup>

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<sup>47</sup> Indeed, the notes from the interviewers often indicate that the patient did not seem to understand the questions or explicitly declared not comprehending the results.

<sup>48</sup> One study found that Mexico City has a high prevalence of late HIV diagnosis, defined as diagnosis when a patient already has  $CD4 < 200$  cell/mm<sup>3</sup>. Late diagnosis can negatively impact anti-retroviral effectiveness and possibly transmission rates. H. Vega-Ramirez et al., "P4.076 Self-Stigma and Unsafe Sex among Mexican Men Who have Sex with Men of the Condesa

Another concern with the results is that unobserved distinctions between high-performing and low-performing clinics may affect the apparent high level of variation between clinics. In Mexico's federalist system of government, the federal AIDS agency CENSIDA sets a baseline level of care required in HIV clinics, but the 32 states have considerable discretion in how generously they fund and manage their HIV clinics.<sup>49</sup> In an interview, one high-level official at CENSIDA in charge of state coordination argued that the differences between clinics might result from political and ideological differences between states, such as the level of fiscal or social conservatism.<sup>50</sup> These ideologies may influence how generously the state's HIV program is supported beyond the federal minimum.

Given the structure of the questions and the pattern of responses, the survey does not enable the discernment of the specific roles of the various mental health staff in the HIV clinics. As noted earlier, the historical role of the Mexican HIV clinic was to provide testing and counseling around initial diagnosis. Some clinics still focus their mental health resources on counseling around an initial HIV+ diagnosis, according to several interviewees.<sup>51</sup> Similarly, the outcome

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Specialized Clinic," *Sexually Transmitted Infections* 89, no. Suppl 1 (July 01, 2013), A312-A312.

<sup>49</sup> Interview with Lucila Villegas Icazbalceta, July 2013.

<sup>50</sup> Ibid.

<sup>51</sup> Interviews with Jorge Saavedra and Carlos del Rio, July 2010. For more on counseling in Mexico, see Eloisa Lara Portal, Antonio Tena Suck and J. Scott Hinkle, "Counseling in Mexico: History, Current Identity, and Future Trends," *Journal of Counseling & Development* 88, no. 1 (2010), 33-37.

variable asks whether or not patients received psychologist support from a specialist. In terms of effective psychological support, whether or not the provider is a specialist may be less important than intangible interpersonal skills, such as empathy and active listening. The high-performing clinics may have nurses or other staff who provide such informal psychological support, which would not be detected by the survey questions. Thus, the mere number of mental health staff per clinic does not lead to a simple conclusion about procedural differences within and between clinics.

#### **2.4.2. Policy Implications**

This study has several important policy implications. The national AIDS program is the most expensive single item covered by the Catastrophic Fund of the Mexican Secretary of Health.<sup>52</sup> Because of its high cost, there has been considerable political pressure on CENSIDA to justify its costs by demonstrating effectiveness. Most of the attention concerns whether mortality rates have dropped considerably since making ARVs universally accessible and free.<sup>53</sup>

Given its ambitious commitment to meeting the general health needs of its HIV+ population, Mexico should take more care to strengthen the mental health care in its national clinics. Adequate psychosocial support may encourage better functioning and thus may minimize morbidity and mortality rates. In fact, since the stress of living with HIV persists even in the absence of a diagnosable mental illness, access to mental health support should not be extended

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<sup>52</sup> Interview with Juan Pablo Gutierrez, July 2013.

<sup>53</sup> Ibid.

only to those HIV+ individuals who meet the official diagnostic criteria for a DSM-IV recognized mental illness.

Such an investment need not be costly relative to the program's existing costs: research suggests that community-based mental health care can effectively and inexpensively treat the mental health needs of HIV+ patients.<sup>54</sup> In fact, it may help control costs by lowering hospitalization: one study of programs in the United States found that HIV+ patients with co-existing substance abuse and mental illness ("triply diagnosed") have been found to have twice the health care costs of the general HIV+ population, in large part because they had more hospitalizations.<sup>55</sup> HIV programs may find it helpful to draw upon recent research on low-cost ways to integrate mental health care into primary care.<sup>56</sup>

In addition to the health service-related recommendations, these findings suggest several upstream programmatic responses that the Mexican HIV program might adopt to improve mental health care in its HIV clinics. First, leading figures in national HIV policy should speak out on

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<sup>54</sup> Blank et al., *Treatment Considerations for HIV-Infected Individuals with Severe Mental Illness* (Springer US, 2013), 1-9.

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<sup>55</sup> Ettner et al., *Tripily-Diagnosed Patients in the HIV/AIDS Treatment Adherence, Health Outcomes and Cost Study: Patterns of Home Care Use*, Vol. 20 (England: , 2008), 1177-1189.

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<sup>56</sup> Robert Beaglehole et al., "Improving the Prevention and Management of Chronic Disease in Low-Income and Middle-Income Countries: A Priority for Primary Health Care," *The Lancet* 372, no. 9642 (, 940-949).

both the importance of mental health for successful ARV adherence and comprehensive HIV care. A second step would be to offer more concrete guidelines for clinics and providers about how to provide mental health services to HIV patients. While currently the Mexico AIDS agency offers a guide to giving psychological care to HIV+ patients, this manual focuses solely on counseling around the initial diagnosis and has not been updated since 1998.<sup>57</sup>

Other steps to improve mental health service delivery in clinics would include making psychological screening a regular aspect of routine care, along with referrals to outside providers if the clinic cannot meet a patient's need. In addition, providing institutional support for patients to form patient-led support groups—for example, by providing space for meetings, and training nurses and non-specialist staff in basic counseling—would all be relatively inexpensive ways to insure that patients receive the mental health care they need. Since the results suggest important differences between women versus men, it raises the possibility that a gender-targeted, two-pronged mental health policy response may be more effective than a uniform approach.<sup>58</sup>

Since there has been virtually no research into the intersection of HIV and mental health in Mexico, much more work needs to be done. Future Mexico-specific research should seek to better understand the concrete ways that HIV clinics screen for, and respond to, patients' mental

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<sup>57</sup> Centro Nacional para la Prevención y el Control del VIH/SIDA. “Guía para la Atención Psicológica” (1998). <http://www.censida.salud.gob.mx/interior/guiasmanuales.html>.

<sup>58</sup> For an example of sex-specific research in a Mexico City HIV clinic, see Vega-Ramirez et al., *P4.076 Self-Stigma and Unsafe Sex among Mexican Men Who have Sex with Men of the Condesa Specialized Clinic*, Vol. 89, 2013), A312-A312.



health care needs.<sup>59</sup> Given that the survey cannot fully explain all the observed findings and the unique answers illuminated by the patients' free responses, a qualitative follow-up study will be important. Through medical chart review, observation and semi-structured interviews with clinic administrators, providers and patients, such a study could both probe the attitudes and beliefs about mental health care among the staff and patients and investigate more clinic-level processes of screening and referrals. Additionally, obtaining state-level or clinic-level budget and expenditure data would allow comparison of the relationship between financing and availability of services.

## **2.5. Conclusion**

The changing nature of the global HIV pandemic makes mental health increasingly relevant as a key predictor of successful lifelong management. In the context of increased longevity of HIV+ patients with ARV treatment, national HIV programs around the world are increasingly aware of and concerned with addressing co-morbid conditions as part of comprehensive HIV/AIDS care. Whether or not to invest more in improved mental health care for HIV patients requires research into the impact of such services on transmission rates, ARV adherence rates, other health outcomes, and programmatic costs. Such technical questions can only be answered through further research into various mental health treatment options tailored to the Mexican HIV+ populations.

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<sup>59</sup> For more on integrating mental health into HIV programs, see Melvyn Freeman et al, "Integrating Mental Health in Global Initiatives for HIV/AIDS," *British Journal of Psychiatry* 187 (2005).

In addition to such technical questions, the issue of whether or not Mexico should address the unmet mental health needs of HIV patients in its care raises ethical concerns.<sup>60</sup> Given the high cost of Mexico's HIV program, reasonable people may disagree about whether it is fair to direct more of the country's scarce resources toward meeting still other health needs of HIV+ patients when the basic needs of other citizens go untreated. On such a view, providing even more resources to the HIV population may seem to represent a new form of HIV exceptionalism, in which HIV is treated differently from other diseases.<sup>61</sup> On the other hand, some may argue that the prior commitment to providing care to this population may create a duty not to discontinue ancillary care.

As HIV transforms from a lethal to a chronic disease, the health needs of those affected will continue to change as well. Countries will have to wrestle with a broader class of concerns similar to the issue of mental health in Mexico: how to make fair and effective priorities that balance the health needs of the HIV+ population alongside those of the general population.

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<sup>60</sup> For more on the ethics of rationing anti-retrovirals, see Norman Daniels, "Fair Process in Patient Selection for Antiretroviral Treatment in WHO's Goal of 3 by 5," *Lancet* 366, no. 9480 (07/09, 2005), 169-171.

See also Sara Bennett and Catherine Chanfreau, "Approaches to Rationing Antiretroviral Treatment: Ethical and Equity Implications," *Bulletin of the World Health Organization* 83, no. 7 (2005).

<sup>61</sup> For more on the idea of HIV exceptionalism and its critics, see Ronald Bayer and Claire Edington, "HIV Testing, Human Rights, and Global AIDS Policy: Exceptionalism and its Discontents," *Journal of Health Politics, Policy and Law* 34, no. 3 (June 1, 2009), 301-323.

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## **PAPER 3**

**What Magic Is There in the Pronoun “My”?**

**The Role of Patients and Disease Advocates**

**in Public Deliberations about Priority Setting in Health Policy**

### 3.0. Stakeholders in Public Deliberations: Between Policy and Philosophy

In recent years, a range of countries have experimented with including non-expert citizens in public deliberations to set priorities for their health policies.<sup>1</sup> Just as in any deliberative enterprise, including citizens offers a host of presumed benefits, both normative and practical. Normatively, some have argued that greater citizen participation may promote fairness of outcomes, while others emphasize the role public deliberation can play in enhancing the perceived legitimacy of, and increased public buy-in to, policy decisions.<sup>2</sup> However, along with these benefits, certain risks arise as well. This paper focuses on one such risk: that non-expert members of the public included in the process are likely to introduce biased or self-interested reasoning that will distort the deliberative process.

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<sup>1</sup> Many different models of public deliberation have been tried. In some countries, these public deliberative processes often entail the specific activities that Health Technology Assessment groups (HTA) conduct specifically to weigh new technologies, rather than broader deliberations over general health priorities. For an example of such a focused HTA group in Sweden, see <http://www.sbu.se/en/>. In other countries, such as the United Kingdom, citizen councils deliberate about such issues as what principles and social values should inform the coverage decisions of the National Health Service. While their reports are supposed to inform the National Council on Clinical Excellence, citizens themselves do not vote on actual coverage decisions. Outside of Europe, countries such as Mexico, Canada, and Colombia have all experimented with such deliberative approaches to priority setting in health policy. On Canadian efforts in British Columbia, see Mark Warren and Hilary Pearce, *Designing Deliberative Democracy : The British Columbia Citizens' Assembly* (Cambridge, UK ; New York: Cambridge University Press, 2008), 237.

<sup>2</sup> Whether deliberation can guarantee fairness, in addition to legitimacy, remains a source of contention. Some, such as Dan Brock, have argued that procedural justice alone, without substantive constraints, cannot guarantee fairness. Others, including Norman Daniels, maintain that adherence to certain standards of procedural justice lead to outcomes that are “defeasibly” fair (i.e., fair, but could be proved to be unfair). This contemporary debate regarding whether deliberative processes are more like pure or impure procedural justice has its roots in Rawlsian notions of fairness and lies beyond the scope of this paper.



All models of citizen participation in deliberations raise many unanswered questions. The topic has been the subject of active academic research.<sup>3</sup> However, one particular category of citizen—the non-expert stakeholder—is especially controversial. Non-expert stakeholder is defined here as a patient or advocate who has a vested, personal, but non-professional and nonfinancial interest in the topic at hand. On this narrower than usual usage, the term non-expert stakeholders include patients, family members of patients and disease advocacy groups. Such stakeholders’ participation in deliberative processes is particularly controversial for reasons I will explain.<sup>4</sup>

This definition would exclude others who might be considered stakeholders in other contexts, such as clinicians (however altruistically motivated), average citizens with no immediate connection to the topic, or industry representatives with a vested financial interest in the

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<sup>3</sup> See Julia Kreis and Harald Schmidt, "Public Engagement in Health Technology Assessment and Coverage Decisions: A Study of Experiences in France, Germany, and the United Kingdom," *Journal of Health Politics, Policy and Law* 38, no. 1 (February 01, 2013), 89-122.

<sup>4</sup> A note on terminology: the common definition of the term ‘stakeholder’ is more expansive than the one I am employing. It would include those with professional or financial interests in the outcome of the deliberation. I have chosen to exclude individuals with those types of interests from this analysis for several reasons. First, there is already a growing portfolio of studies on topics related to how professional self-conception affects decision-making and how financial interests sway physicians’ views. For example, see Maryam Kouchaki, “Professionalism and Moral Behavior: Does a Professional Self-Conception Make One More Unethical?” Edmond J. Safra Working Papers, No. 4 (2013).

Cognitive dissonance theory has been used to explain why transparency policies, such as policies of disclosing financial conflicts of interest, may not prevent biased decision-making. For example, see Lisa Cosgrove and Robert Whitaker, “Finding Solutions to Institutional Corruption: Lessons from Cognitive Dissonance Theory,” Edmond J. Safra Working Papers, No. 9 (2013). The normative and practical implications of these general findings for public deliberations with stakeholders, by definition biased, have received less specialized attention.

outcome.<sup>5</sup> The reason for this narrow focus on patients and disease advocates is that they exhibit both privileged understanding of the topic, as well as a strongly motivated interest in a certain outcome. Despite the rise in policymakers' interest in including such groups, concern remains about the benefits of their participation in deliberation.

Further, I contend that the applied question of whether or not to include stakeholders in deliberations poses conceptual difficulties because it throws into stark relief deeper undercurrents of tensions within deliberative theory and practice.<sup>6</sup> Clarifying what those conceptual risks and benefits of stakeholder participation are is one goal of this paper.

Non-expert stakeholders can exert enormous power to influence health resource allocation and thus trajectories of population health. Indeed, successfully prioritizing a disease onto the policy agenda often requires years of passionate, committed efforts of patients, friends and family, and disease advocacy groups as much or more than the efforts of physicians or other experts.<sup>7</sup> For example, after pioneering what is now the gold standard of activism campaigns, HIV advocates,

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<sup>5</sup> Of course, the probabilistic nature of disease means that all citizens share the risk of contracting disease in the future. However, that risk in average citizens does not provide the same degree of emotional salience as the presence of the disease in different stakeholders to make the situations normatively comparable.

<sup>7</sup> The participation of experts as "objective" has been found to vary depending upon empirical conditions. See Christopher Tarver Robertson, "Blind Expertise," *NYUL Rev.* 85 (2010), 174.

many of them HIV+, transformed the landscape of available resources for research, prevention and care.<sup>8</sup>

Conversely, in cases where stakeholders are silent and do not organize to allocate resources to their given disease, policymakers may find it all too easy to neglect it. A common reason for silence and political neglect is stigma. Mental health and rare diseases tend to fall into this latter category, as do many other neglected diseases. The practical challenge raised by stigmatized diseases is to create a standardized, fair process that avoids ad hoc decisions based on public stigma. Stakeholders can counteract stigma under certain circumstances. Another goal is to minimize the disproportionate influence by groups based on factors, such as wealth or socioeconomic power, ethically irrelevant to their medical issues.

As a normative issue, I argue that the real-world, practical problem of involving stakeholders in deliberation raises philosophical concerns that merit more rigorous scrutiny than they have received. Specifically, I analyze this real-world problem through the lens of the longstanding philosophical tension between partiality and impartiality in moral and political philosophy.<sup>9</sup>

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<sup>8</sup> Epstein, *Impure Science : AIDS, Activism, and the Politics of Knowledge*, Vol. 7 (Berkeley: University of California Press, 1996), 466.; Randy Shilts, *And the Band Played on : Politics, People, and the AIDS Epidemic*, 20th anniversary ed. (New York: St Martin's Griffin, 2007), xxiii, 630 p.; Brandt, *How AIDS Invented Global Health*, Vol. 368 (Massachusetts Medical Society, 2013), 2149-2152.

<sup>9</sup> This tension between partiality and impartiality is not exclusive to the problem of stakeholders, or even public deliberation. It is a perennial tension in moral and political philosophy. Thus, this paper's focus is narrower than the broader philosophical discussion on partiality and impartiality; additionally, the focus is narrower than broader public deliberations about health policy. Here I am focusing on specific processes of deliberation as such, not other forms of public speech that may influence political decision-making. P. J. (P Kelly, *Impartiality, Neutrality and Justice : Re-*

Many philosophical accounts of good decision-making hold that impartiality should prevail.<sup>10</sup>

Thus, all aspects of a deliberation—its values, its choice of participants, and its procedural standard—should reflect and encourage impartiality.<sup>11</sup> As an ideal standard, impartiality can be compelling. As a standard for real-world action, however, impartiality leaves unresolved many aspects of real-world decision making.

For example, against this ideal of impartiality, a personal (rather than financial) conflict of interest arises between individuals' role as impartial deliberators and partial stakeholders. Indeed, stakeholders who would participate in a deliberation about public policymaking must navigate a tricky dual role. They must wear "two hats," holding in tension both the first-person (partial) and third-person (impartial) perspective. Once they assume the role of deliberators, they also assume the corresponding duty to seek mutually satisfactory outcomes with fellow participants, which their vested interests may impede. Because stakeholders' very inclusion in deliberations stems from their identity as partial actors, the choice to include them or not hinges on the extent of the

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*Reading Brian Barry's Justice as Impartiality* (Edinburgh: Edinburgh University Press, 1998), 261.

<sup>10</sup> Brian Barry famously makes this point explicit, though he is not alone in this equation of good reasoning with impartial reasoning. See Brian Barry, *Justice as Impartiality* (Clarendon Press Oxford, 1995).

<sup>11</sup> This characterization is a broad gloss on the topic; it will not fit every example of deliberative theory. Dennis Thompson had argued against depicting theory in a heavy-handed way that will render it a caricature. Dennis F. Thompson, "Deliberative Democratic Theory and Empirical Political Science," *Annual Review of Political Science* 11, no. 1 (06/01, 2008), 497-520.

risk that their necessarily partial views will be misleadingly and destructively, rather than just benignly, partial.

### *3.0.1. Methodological Approach*

This specific issue of the participation of non-expert stakeholders in deliberation warrants closer attention. Yet despite the necessity of selecting participants for deliberative practices, whether or not to include stakeholders remains unresolved, both normatively and empirically. Despite the growing literature on general deliberative theory, the more applied aspects of managing a deliberation—how to select citizens and non-expert deliberators and how to decide what their function should be within a deliberation—remain less explored and more uncertain.<sup>12</sup> The question becomes: how should deliberative designers manage the risks that such participation of partial, non-ideal deliberators will not undermine the process?<sup>13</sup>

Such lack of resolution is complicated by the fact that deliberative theory has not wholly shed an unrealistic standard of impartiality. In the face of impartiality as the dominant deliberative ideal, I argue for a more robust theory of participation in deliberation. In this case, stakeholders' value to the deliberative exercise rests precisely in their partiality; by expressing their unique views

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<sup>12</sup> This question raises fundamental issues of democratic theory, such as democratic representation, that go beyond the scope of this paper. Carolyn M. Hendriks, "Integrated Deliberation: Reconciling Civil Society's Dual Role in Deliberative Democracy," *Political Studies* 54, no. 3 (2006a), 486-508.

<sup>13</sup> Such accounts often pay little attention to civil society. Carolyn M. Hendriks, "Integrated Deliberation: Reconciling Civil Society's Dual Role in Deliberative Democracy," *Political Studies* 54, no. 3 (2006a), 486-508.

they make an epistemic contribution. For example, providing first-person accounts of the phenomenology of a given illness can shed light on an otherwise misunderstood topic. This enrichment of the informational base of the deliberation ultimately may lead to more fully informed, legitimate, and fairer process and outcomes.

This specific argument rests on a deeper argument about the nature of good decision making in the real world. A more abstract goal of this paper, then, is to specify how exactly partiality enriches deliberation. Impartiality in the real world becomes a more pragmatic notion, reached through the social vetting of partial views. I argue, not against the existence of deliberative standards, but for a workable approach to deliberation, one grounded in the contingencies of human psychology and personal commitments. One implication of this view on partiality is that the potential contributions of non-expert stakeholders, viewed as partial actors, warrants greater attention.

I develop this core argument across three sections. Section 3.1 sketches, with broad brushstrokes, classic deliberative theories to explain why impartiality represents the ideal and partiality seems to add risks and threats to good deliberation. Acknowledging the potential for bias outlined in Section 3.1, Section 3.2 turns to the converse issue: to demonstrate the compatibility of partiality with good decision-making. To examine the claim, Section 3.3 turns to the real-world implications of the arguments developed in the first two sections. It does so by investigating a hypothetical scenario of whether or not a Minister of Health should invite disease advocates to participate in a deliberation to help update the national policy guidelines and budgetary allocation for that disease. This section details some key concerns the Minister of Health should

consider in deciding whether, or how, to include the disease advocates in this process. The paper concludes with thoughts on a future research agenda.

A robust account of reasons to include stakeholders in deliberations can help improve priority setting for health. By excluding non-expert stakeholders due to their partiality, such processes will continue to be dominated by elites, technocrats and politicians. Those advocacy groups who get an audience may be those whose wealth buys them access. Public participation in health priority setting can contribute to increased fairness and legitimacy of decisions. Yet achieving a beneficial model of such inclusion requires a principled, empirically grounded approach that expands inclusiveness while identifying and minimizing the risks that such inclusion introduces.

### 3.1. The Role of Impartiality in Classic Deliberative Theory

This section outlines why deliberative theory has upheld impartiality as the gold standard for deliberation, and by extension, why partiality poses risks to good deliberation. First, I describe the important role that impartiality has played in prominent approaches to democratic deliberative theory. One clear implication of impartialist theories is that they would exclude any deliberators who do not hold an impartial stance toward the outcome, such as stakeholders. However, I suggest that this exclusion presents several problems, both for theory and for democratic decision making in the real world.

Deliberative democratic theory emerged in the 1970s and 1980s, with Jurgen Habermas as a primary pioneer who took inspiration from his experiences in the sophisticated salons of Paris.<sup>14</sup>

Many definitions of deliberation compete, and sketching a singular description of what democratic deliberative theory means or holds is to risk oversimplifying a family of views.

Armed with this caveat, here, I divide the realm of theory into the earlier “classic” or “traditional” deliberative theory, which will be contrasted with the “updated” or “recent” “expanded” models.<sup>15</sup>

#### 3.1.1. *Deliberative Democratic Theory*

The problem of stakeholder participation in priority setting for health recalls what Rawls referred to as the “paradox of public reason.” Individuals have comprehensive worldviews that are reasonably plural; yet to make decisions about justice and political issues, these individuals need

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<sup>14</sup> Hendriks, “Integrated Deliberation.”

<sup>15</sup> The former will be featured here in Section 3.1 of the paper, and the latter will figure more heavily in Section 3.2.



to set aside these worldviews. The very notion that there could be such a thing as public reason seems paradoxical. As Rawls set up the problem:

Why should citizens in discussing and voting on the most fundamental political questions honor the limits of public reason? How can it be either reasonable or rational, when basic matters are at stake, for citizens to appeal only to a public conception of justice and not to speak the whole truth as they see it? Surely, the most fundamental questions should be settled by appealing to the most important truths, yet these may far transcend public reason! John Rawls, *Political Liberalism*, Vol. 4 (New York: Columbia University Press, 1996), 464.

Public deliberations offer a concrete approach for overcoming, if not resolving, the paradox of public reason. In Rawls' view of political liberalism, for example, such discussions should strive for mutual justification; this effort itself will tend to lead to the 'internalization of the common good.'<sup>16</sup> By presenting a normative ideal of mutual justification, deliberative theory serves to articulate how partial individuals can participate in public discussions of collective problems.

Deliberative democratic theory is an umbrella term that encompasses various approaches.

Nevertheless, certain conceptual criteria characterize deliberative theory.<sup>17</sup> Analyzing the

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<sup>16</sup> Ibid.

<sup>17</sup> Thompson, *Deliberative Democratic Theory and Empirical Political Science*, Vol. 11, 2008), 497-520.

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common features help to explain why and how deliberative theory can be understood to promote impartiality as the procedural ideal.

Despite minor differences, there is general agreement on the core features of deliberative democracy. Political theorist Dennis Thompson defines the fundamental question of deliberative democracy to be: “in a state of disagreement, how can citizens reach a collective decision that is legitimate?”<sup>18</sup> Similarly, Carolyn Hendriks holds that: “Deliberation is an activity that takes place in structured fora where free and equal participants come together to decide on an agenda, reason and argue together and settle on an outcome.”<sup>19</sup>

Note that in both definitions the concept of ‘deliberation,’ as employed in deliberative theory, departs from common usage. The idea has specific normative meaning. Specifically, the reference to “free and equal participants” emphasizes that the deliberative ideal rejects any role for power, strategy or self-interest. In this way, deliberation has been defined precisely in opposition to other forms of group discussions, such as negotiation or bargaining, that assume the presence of power dynamics, clashing interests, and self-concern.<sup>20</sup> Deliberation connotes an ideal process that does not resemble the messiness of real-world arguments or negotiations.

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<sup>18</sup> Ibid.

<sup>19</sup> Hendriks, “Integrated Deliberation.” For other definitions of deliberations, see James Bohman and William Rehg, *Deliberative Democracy : Essays on Reason and Politics* (Cambridge, Mass.: MIT Press, 1997b), 447.

<sup>20</sup> Jane Mansbridge et al., "The Place of Self-Interest and the Role of Power in Deliberative Democracy," *Journal of Political Philosophy* 18, no. 1 (03, 2010), 64-100.

Another distinguishing feature of democratic deliberation is its emphasis on reaching a “collective decision” or “settling on an outcome.” Specifically, the ideal holds that through deliberation all participants would ultimately converge in consensus. (This avoids the need to resort to non-deliberative methods, such a majority vote, to decide on the outcome). This focus on consensus, however, does not imply that one singular best decision should always prevail. Reasonable pluralism and cultural influences mean that different groups may reach different decisions.

### *3.1.2. Why has impartiality seemed to be the procedural ideal of deliberative theory?*

Having sketched the features of the classic deliberative democratic model, the conceptual linkage with impartiality as a procedural ideal becomes clear. Earlier formulations of deliberative theory expressed an explicit commitment to impartiality as the ideal. For example, Brian Barry called his theory of justice “justice as impartiality” (modeled after Rawls’ ‘justice as fairness’).

This normative commitment to impartiality has real-world implications for the design of deliberative processes. Most relevantly, it would reject stakeholder inclusion in democratic deliberation as a nonstarter. As Hendriks notes, in deliberative theories “the key emphasis... is that participants are relatively impartial, willing to listen to each other and committed to reaching a mutual understanding...of the common good.”<sup>21</sup> Given this description of ideal participants,

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<sup>21</sup> Carolyn M. Hendriks, "Integrated Deliberation: Reconciling Civil Society's Dual Role in Deliberative Democracy," *Political Studies* 54, no. 3 (2006b), 486-508.

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vast swaths of civil society would be excluded. At the extreme, deliberations could not include any kind of partial actor, and certainly not stakeholders such as “interest groups, social movements and activists.”<sup>22</sup>

Indeed, there are real risks to stakeholder participation in deliberation. The rationale for excluding stakeholders stems from the same concerns that lead to impartialist theoretical approaches. The risk is that the benefits of impartiality would be undermined by the biased participation of interested parties.

The presentation of biased opinion as impartial fact may mislead discussions so that they result in incorrect conclusions. Indeed, history shows that partiality can lead not only inaccurate understanding of a given problem, but also to morally reprehensible ones. For example, in Nazi Germany psychiatrists took part in a project to exterminate mentally ill patients. During a 1940 planning meeting, several psychiatrists opposed the medical killing project. However, then a professor of “considerable professional standing spoke passionately of having lived through the tragedy of coping with a mentally ill brother-in-law” as a way of trying to persuade the group not to oppose exterminating the mentally ill. Here, he used his (supposedly real) connection with the issue to argue in favour of a morally reprehensible policy successfully enough that several psychiatrists changed their minds and now supported the project.<sup>23</sup>

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<sup>22</sup> Ibid.

<sup>23</sup> Peter Barham, *Closing the Asylum : The Mental Patient in Modern Society*, 2nd ed. (London ;New York: Penguin, 1997), xv, 214 p.

The potential for the transformation of preferences is an essential component of deliberative democracy. In an additional contrast with aggregative or interest-based approaches to decision making, deliberation rests on the presumption that having to justify one's beliefs to others, rather than simply arguing for them, will lead to better decision, in part because solely self-interested motives will recede into the background.<sup>24</sup> Participants may change their minds based on consideration of arguments expressed by others. Thus, even when consensus cannot be realized, the collective search for mutual justification will still result in better decisions than mere aggregation of pre-deliberative preferences.

Partiality appears to undermine good deliberation in part because it seems to cut off the possibility of transformation. A related risk is that stakeholders' vested interests would undermine their motivation and ability to seek mutual justification. Their dual role—as stakeholders representing a specific perspective and deliberators tasked with seeking common solutions—would be incompatible. Thus, partiality threatens deliberation because it seems to imply not just a unique perspective, which may have informational and normative value, but an inflexible form of partisanship that would undermine the possibility of mutual agreement.

In order to avoid bias and power-based negotiations, various mechanisms have been suggested to cultivate impartiality and shield the process from the corrupting influence of individuals' partial perspectives. Adam Smith's impartial spectator, Rawls' veil of ignorance, Barry's expansion of

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<sup>24</sup> Note that the mere and common stipulation that individuals have a motivation to seek mutual justification does not eliminate self-interest.

Scanlon's contractualism to the sphere of justice—what links these disparate ideas is that they all involve a core commitment to impartiality.<sup>25</sup>

To achieve impartiality, the classic model seeks to eliminate the supposedly corrosive impact of partiality through procedural constraints on certain forms of expression and idealized notions of human motivation.<sup>26</sup> For example, just as had prevailed in the Parisian salons of Habermas' memory, classic versions of deliberation mandate rational, well-articulated arguments and non-emotional, verbal forms of expression.<sup>27</sup>

Impartialist approaches offer some suggestions for how participants can transcend their own narrow frame of reference. Various theorists have imagined how to overcome individuals' inherent partiality. Beyond its original usage, the Rawlsian veil of ignorance has been invoked as a thought experiment to approximate impartiality in many decision scenarios. By excluding one's known personal characteristics as irrelevant, the veil of ignorance helps ensure that

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<sup>25</sup> The term impartiality can refer to individuals (in the sense of having an equal disposition toward all) and a procedural issue (a law can be applied impartially, without deviation based on personal considerations). In either usage, impartiality is always a relational concept. One is always impartial or partial with respect to something.

<sup>26</sup> On where to draw the line between other forms of small group discussion and deliberation, see Tali Mendelberg, "The Deliberative Citizen: Theory and Evidence," *Political Decision Making, Deliberation and Participation* 6, no. 1 (2002), 151-193.

<sup>27</sup> Some may object that the veil of ignorance was not intended to apply to fine-grained real world concerns, but also to issues of basic justice such as exist in the Rawlsian Original Position. Regardless of the intended narrowness of the original veil, veil of ignorance techniques have entered the mainstream as general categories of concern that would require stretching beyond one's own view. Thus they are legitimately invoked here as real world techniques.

excessively partial considerations cannot and do not play in the arguments offered.<sup>28</sup> Yet in the specific policy questions often at stake in deliberations, the participants are expected to argue from their known point of view, leaving a Rawlsian-inspired veil experiment as a useful, but incomplete, means of fostering third-party perspectives.

All these practical measures serve the same purpose: to foster impartial thinking and decrease the influence of partiality on deliberators' reasoning. Impartiality should prevail in the discourse, participants' stance, procedural issues, epistemic investigation, and final outcome. Note that impartiality need not mean that one single, correct answer exists. Rather, the final decision, regardless of its substantive meaning, can be considered impartial if it was reached through impartial means.<sup>29</sup>

### *3.1.3. Non-exclusionary Deliberative Processes*

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<sup>28</sup> Eric Anthony Beerbohm, *In our Name: The Ethics of Democracy* (Princeton University Press, 2012).

<sup>29</sup> Depending on factors such as participant composition, deliberative purpose or informational materials, an impartial or fair process may or may not be a legitimate one. For a deliberative process that claims to be a democratic, one that includes a wider range of stakeholders would, *ceteris paribus*, tend to lead to more political legitimacy than a wholly technocratic one. Determinants of legitimacy are multidimensional, like deliberative values themselves. My argument about the importance of partiality does not depend on predictions of legitimacy, although this is a likely outcome. For more on legitimacy in deliberations, see Eric Anthony Beerbohm, *In our Name: The Ethics of Democracy* (Princeton University Press, 2012).; Thompson, *Deliberative Democratic Theory and Empirical Political Science*, Vol. 11, (2008), 497-520.

Not all approaches to deliberative processes seek to exclude partial perspectives. For example, Amartya Sen's idea of "open impartiality" illustrates that theories of justice that promote impartiality actually leave conceptual room for partiality.<sup>30</sup> Sen defines "closed impartiality" as the dangerous status quo in which only participants from within a group can weigh in on a choice. The limited range of perspective of this closed group threatens to lead to "procedural parochialism." Achieving true impartiality would require what Sen calls casting "a wider net of partiality."<sup>31</sup> Gathering such partial perspectives will expand the range of considerations and thus will help avoid what Sen calls the "problem of exclusionary neglect," which represents the concern that certain considerations and interests will only come to light when a broader range of affected parties are able to express their points of views.<sup>32</sup> Sen's idea of open impartiality represents a hybrid ideal: reaching impartiality through the embrace of partiality. Yet how to achieve impartiality even in theory remains a challenge.<sup>33</sup>

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<sup>30</sup> Amartya Sen, "Open and Closed Impartiality," *Journal of Philosophy* 99, no. 9 (2002).

<sup>31</sup> Ibid.

<sup>32</sup> Advocating broader inclusivity in constituting the demos, Sen expands the original position to include the perspectives of all those who may be affected by a decision, including those outside that society. This general concept of a major expansion of the demos has been challenged and embraced by other theorists. For more, Goodin's view that "all affected parties" should participate in the vote does not imply a radical expansion of the franchise to include "all possibly affected parties." See Robert E. Goodin, "Enfranchising all Affected Interests, and its Alternatives," *Philosophy & Public Affairs* 35, no. 1 (2007), 40-68.

<sup>33</sup> Sen invokes an Impartial Spectator (modeled after Smith's eponymous concept). With a perfect ability, the Impartial Spectator will adjudicate the relative merit of multiple perspectives so as to reach impartiality. However, *how* the Impartial Spectator would accomplish this perfect evaluation remains vague.



Other approaches to deliberative processes recognize the importance of stakeholders to real-world decision-making. One such example is a procedure called “Accountability for Reasonableness” (A4R), developed by Norman Daniels and James Sabin.<sup>34</sup> A4R is a normative and practical framework for a fair deliberative process. It specifies four conditions that a process must meet to be considered fair and legitimate: publicity, relevance, appeals and enforcement.<sup>35</sup> Many countries and academic studies have used the four conditions of A4R as benchmarks by which to design and evaluate the fairness and legitimacy of a deliberative process.<sup>36</sup> A key insight raised by A4R is that deliberations need not always be democratic to be fair. Because earlier formulations of A4R focused on private sector decision making, the framework remained silent on participant selection.<sup>37</sup> In certain contexts, such as the private sector or national-level policymaking, deliberations may only include bureaucrats or experts; the publicity requirement will serve to achieve accountability and legitimacy. Yet when implementing

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<sup>34</sup> Norman Daniels, *Just Health: Meeting Health Needs Fairly*, Cambridge, U.K.; New York: Cambridge University Press, 2008.

<sup>35</sup> A source of some contention in the literature has been whether these four criteria are sufficient to ensure that the outcome of the decision is fair, or if it can merely guarantee a form of procedural legitimacy. Whether or not this central claim is true is beside the point for this discussion.

<sup>36</sup> For example, the National Institute of Clinical Excellence in the United Kingdom has employed A4R when developing citizens’ councils on eliciting social value judgments in health. S. Maluka et al, “Decentralized Health Care Priority-Setting in Tanzania: Evaluating against the Accountability for Reasonableness Framework,” *Social Science & Medicine* 71, no. 4 (2010); S. L. Sibbald et al, “Evaluating Priority Setting Success in Healthcare: A Pilot Study,” *BMC Health Services Research* 10 (2010).

<sup>37</sup> This silence about participant selection in a fair deliberative process reflects A4R’s private-sector origins. Initially, A4R was a tool for private managed care organizations to justify to enrollees in their health plans the reasons behind their decisions to cover a given treatment or not. See Norman Daniels and James Sabin, “The Ethics of Accountability in Managed Care Reform,” *Health Affairs* 17, no. 5 (1998).

deliberative processes in public policy contexts, the authors have argued, a broader range of participants and stakeholders should be included.<sup>38</sup> A public process can take many forms. For example, British Columbia experimented with a deliberative democratic process for electoral reform by enlisting a representative swath of citizens, randomly selected, to develop a proposal for electoral reform. These citizens participating both non-deliberatively by studying and contemplating on their own and deliberatively, by coming together for an in-person discussion.<sup>39</sup>

The claim that that deliberation and democratic participation are not synonymous underscores that deliberation does not alone imply inclusion or exclusion of stakeholders.<sup>40</sup> In short, fair process and democratic representation must be distinguished as complementary, but distinct, concerns.<sup>41</sup> Who participates in the deliberation and whether or not it is fair and legitimate are

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<sup>38</sup> Note, however, that this silence does not imply that A4R is powerless against cooption by special interests. It manages the risk of bias through the public justification of the final decision in terms that all participants can agree are relevant.

<sup>39</sup> Warren and Pearse, *Designing Deliberative Democracy : The British Columbia Citizens' Assembly* (Cambridge, UK ; New York: Cambridge University Press, 2008), 237.

<sup>40</sup> To be clear, more recent work on A4R has focused on public systems and called for the inclusion of stakeholders. The original non-inclusion of stakeholders represented a political compromise in the US context where A4R first was developed, since private health plans could not be compelled legally to include a broad range of stakeholders in deliberations. For early work, see James E. Sabin and Norman Daniels, "Making Insurance Coverage for New Technologies Reasonable and Accountable," *Journal of the American Medical Association* 279, vol. 9 (1998); Norman Daniels, "Accountability for Reasonableness," *British Medical Journal* 321 (2000).

<sup>41</sup> Mark Warren and Hilary Pearse, *Designing Deliberative Democracy : The British Columbia Citizens' Assembly* (Cambridge, UK ; New York: Cambridge University Press, 2008), 237.

separate questions; this insight raises the possibility of a fuller defense of fair stakeholder participation in deliberative processes. Such a defense would require articulating the empirical and normative pros and cons of stakeholder inclusion and showing that the benefits outweighed the risks.

#### *3.1.4. Limits of Impartiality*

This section has explained the appeal of impartiality as the ideal of deliberative theory. As the discussion of the classic deliberative ideal and its related criteria show, partiality seems to threaten to undermine some of the fundamental components of the deliberative ideal. Impartiality has an important role to play in good decision-making. One correct insight of the classic model is to identify the real risks of unfettered partiality, most broadly that it will introduce bias that will distort decision-making. Yet, as the examples of open impartiality and A4R demonstrate, a wholesale commitment to impartiality does not allow for the potential benefits of partiality. Such exclusion actually undermines, rather than enhances, good deliberation. Partiality offers specific values to deliberation, as the next section will argue.

### **3.2. The Value of Partiality in Deliberation**

Impartiality represents an understandable though limited ideal of deliberation. Despite the real risks that partiality will lead to biased decision making, partiality remains a valuable component of deliberation. This section turns to the complementary issue of partiality. The relevant question is not whether or not partiality can have merit. Rather, the challenge is to clarify, with more conceptual granularity, how partiality can add value to deliberations.

Many skeptics will still fear that partiality can detract from good deliberation. Thus, this section offers a defense against the common, even intuitive, view that partiality will tend to harm deliberation. This section aims to advance a conceptual defense of partiality's positive value for deliberation. There are several ways that partiality can enhance, rather than detract from, good decision-making: through morally-acceptable self-interest, compatibility with correctness, epistemic value, and the power of irrelevant arguments to stimulate further deliberation. After fleshing out each of these dimensions, I then present some objections that an impartialist skeptic may raise in response to the preceding discussions of the positive aspects of partiality. Overall, the goal is to better understand first, the conceptual dimensions in which partial perspectives matter to good deliberation and secondly, how these perspectives may work or fail to work in practice (which will be the subject of Section 3.3).<sup>42</sup>

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<sup>42</sup> While the points brought up here raise many empirical questions, this section's approach to partiality is primarily conceptual, not empirical. The empirical implications of these conceptual issues are the subject of Section 3.3. Since the overall project is to develop a pragmatic alternative account of partiality in good decision making, moving between theory and such a real world test is critical to this project.

### 3.2.1. Partiality

Before turning to the positive aspects of partiality, it should be noted that excluding partiality from deliberation is not a truly feasible goal. Having a partial perspective is an intrinsic component of experience. Moreover, the boundaries between impartial and partial reasons will not always be conceptually clear or accessible to us. In certain cases, this indecipherability reflects a basic epistemic opacity of people's motivations (including one's own). In other words, the grounds or motivations for holding a view are often unknowable. Nor will self-reflection reveal the truth, since the importance of a problem to an individual is often influenced by partial considerations that may or may not be cognitively accessible. For example, I might become a psychiatrist because I think I love science, but a deeper reason may be that I saw a loved one suffer from mental illness in my own childhood.<sup>43</sup>

These cognitive biases do not belong exclusively to the purview of stakeholders, but are features of human psychology in general. Empirical research has documented the power of non-verbal forces in shaping our cognitive processes and even moral reasoning.<sup>44</sup> Such cognitive biases

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<sup>43</sup> To give an example of the disconnect between the cause of intuitions and the recognition that something should count as a reason, Daniel Kahneman describes a study in which participants must decide on the appropriate level of compensation for a man shot during a robbery. Some were told one version while the others were told a much more poignant story that emphasized the randomness of the shooting. Those who had heard what Kahneman called the "poignant" second scenario decided on a median compensation level \$100,000 higher than the non-poignant group. Daniel Kahneman, "Can We Trust Our Intuitions?" In *Conversations on Ethics*, by Alex Voorhoeve, Oxford, U.K.: Oxford University Press, 2009, p. 74. Other research has shown that participants do not believe that poignancy is a good reason to award higher compensation.

<sup>44</sup> Most prominent among this growing body of work is that of the Nobel Prize-winning duo Daniel Kahneman and Amos Tversky. See Daniel Kahneman, *Thinking, Fast and Slow*, 1st ed. (New York: Farrar, Straus and Giroux, 2011), 499.

make us poor judges of biases on our thinking. Further, the basic opacity regarding the sources of preferences and knowledge means that they will not always result in a clean division into black or white categories of impartial and partial.<sup>45</sup>

Indeed the classic model of deliberation requires an impractical level of self-transcendence.

Beerbohm wryly refers to such a model individual as “the heroic figure of the “superdeliberator.”<sup>46</sup> If only a superhuman could overcome the natural instinct to argue from self-interest, then deliberation would not have much success.

The inevitable ‘smuggling-in’ of partiality undermines the classical understanding of the deliberative process. The vocal expression of articulated reasons is but one, and possibly not the most influential, of the factors that determine the outcome of a public deliberation. While excluding the expression of partial *reasons* during a deliberation is achievable through rules

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Further, recent research suggests Kahneman and Tversky’s conclusions by demonstrating that bringing these biases to attention helps, but does not solve the problems of blind spots. For example, even reminding people that they are likely to have a certain bias does not eliminate that bias. Kouchaki, “Professionalism and Moral Behavior.”

<sup>45</sup> Making a similar point, Kahneman critiques Frances Kamm’s method of testing her own intuitions: “So I would sharply separate the different phases in Kamm’s description of her method: the first phase, where she knows what she would do, and the second phase, in which she thinks deeply as to why she would do it and come up with a reason. It is at least possible that the reason she comes up with was not the cause of her judgement.”

<sup>46</sup> Beerbohm, *In our Name: The Ethics of Democracy* (Princeton University Press, 2012).

about permissible forms of speech, partiality cannot be entirely eliminated from real-world deliberative processes.<sup>47</sup>

### *3.2.2. How Partiality Contributes to Deliberation*

Here I detail some ways that partiality may enhance deliberation.

#### *3.2.2.1. Epistemic Value of Partiality*

The first way that the partiality of stakeholders can add value to a deliberation is through its unique forms of knowledge that stakeholders are privy to due to their affiliation with the topic in question. The procedural aspects of deliberation contain several types of truth seeking. One is the search for reliable and relevant facts about the subject; these forms of knowledge are the technical kind that experts, such as clinicians or economists, are expected to have superior ability to contribute. As the previous discussion of Sen's open impartiality showed, the instrumental advantages of sampling a wide variety of different perspectives are not controversial. But the nature of deliberation is not just the aggregation of individual truths.

Even irrelevant or bad arguments can play a valuable instrumental role in clarifying and refining arguments.<sup>48</sup> A concrete example illustrates this point. During a deliberation, I may assert that

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<sup>47</sup> For example, Elster predicts that self-interest will always influence one's view of the common good. As he writes, "private benefits may causally determine the way in which one conceives of the common good."

<sup>47</sup> The greater danger is that participants may not treat their own views with as much skepticism as is warranted.

<sup>48</sup> This claim recalls the discussion in Section 3.1 about "Accountability for Reasonableness." A4R's "relevance condition" states that the reasons given for a decision must be considered relevant by all "fair-minded" participants. This requirement of mutual justification—a hallmark of deliberation in general—can be understood as a way to manage the risk of partiality. The

my son should get a given drug because he is my son and I love him. Hearing this partial argument, someone else might counter my claim by responding that his son is no different than anyone else's son. In the end, this discussion may result in the consensus view that everyone's child has equal importance.<sup>49</sup> Alternatively, the group of deliberators might use that initial partial comment to reach the more general principle that "priority to the young" would be a principle that could be accepted by the whole group.

The key is that neither of these results supports the wholly partial idea that my son should get the treatment on the grounds that he happens to be my son. In certain cases, the expression of irrelevant arguments may have the paradoxical effect of pushing individuals towards greater impartiality.<sup>50</sup> The reason-giving requirement can sometimes cause deliberators to reflect on the soundness of their own and others' arguments, and revise when necessary.

In addition to objective or technical facts, deliberators contribute subjective perspectives on the issue at hand.<sup>51</sup> In other words, deliberators contribute to the success of the exercise by raising

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condition does not require that all participants agree on the relative weights of reasons, simply that all reasons that prevail are ones everyone can accept.

<sup>49</sup> Brian Barry makes a similar claim that public reflection on partial concerns could lead to acknowledgement that some questions are better settled through impartial reasoning. Brian Barry, *Justice as Impartiality* (Oxford: Clarendon Oxford, 1996).

<sup>50</sup> As discussed, partial views can enhance or distort deliberation. Which one they are more likely to do remains an ambiguous empirical issue.

<sup>51</sup> For more on the idea of democratic deliberation as social epistemology, see Elizabeth Anderson, "The Epistemology of Democracy," *Episteme: A Journal of Social Epistemology* 3 (2006).



what they view as relevant issues and testing the soundness of their idea against the opinions of the group. Such subjective opinions, rather than facts, expressed in the deliberative forum may provide key insight into otherwise unexpressed aspects of the topic under consideration.

For example, first-hand accounts of illness offer unique value that cannot be replaced with expert analysis. The lived experience of a disease is not accessible to those who do not suffer from it.<sup>52</sup>

The basic unknowability gives stakeholders a unique epistemic relationship to the issue at hand.<sup>53</sup> Autobiographical accounts of life with stigmatized conditions capture the phenomenology of the illness in a way that the most meticulously planned social science research cannot. Memoirs of living with HIV/AIDS show the experiential dimension—like being “exiled on the moon”—that more dispassionate research necessarily cannot capture. (Semi-structured interviews may come closest to approximately this experience.)<sup>54</sup> Indeed, expecting the very ill to deliberate in an impartial way may be impossible. Susan Sontag, in her well-

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<sup>52</sup> See, for example, Nancy Scheper-Hughes, *Saints, Scholars, and Schizophrenics : Mental Illness in Rural Ireland*, 20th anniversary, updated and expanded. ed. (Berkeley: University of California Press, 2001), xxviii, 389 p.

<sup>53</sup> Elaine Scarry, *The Body in Pain : The Making and Unmaking of the World* (New York: Oxford University Press, 1985), vii, 385 p.

<sup>54</sup> Paul Monette, *Borrowed Time: An AIDS Memoir*, San Diego, Calif.: Harcourt Brace Jovanovich, 1988, quoted in “Sae Takada, *Quality of Life, Health-Related Stigma, and the Social Context: Longitudinal Analyses of PLWHA in Uganda and a Literature Review*, 2012).

known work, *Illness as Metaphor*, points out that those dying of cancer were “robbed of all capacities of self-transcendence.”<sup>55</sup>

This insight that deliberations about illnesses must combine subjective with objective claims implies that experience-based contributions may enhance deliberations. Non-expert stakeholders need not speak with the same impartiality or authority as some experts.<sup>56</sup> Rather, they can contribute as individuals who are, as Sontag famously wrote, “citizens in the kingdom of the ill.”<sup>57</sup> Their words help to illuminate this world to those who, for now, remain in the kingdom of the well.

Indeed, an insistent reliance on traditional models of quest for impartiality can lead to worse outcomes, particularly when deliberating about resource allocation for stigmatized diseases. In such cases, the importance of “epistemic humility” on the part of deliberative designers, experts and other non-interested deliberators becomes crucial. Such deliberations should aim for greater inclusiveness of partial participants, in acknowledgment that the patient or disease advocate’s

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<sup>55</sup> Paradoxically, Sontag is precisely expressing the fear of impartialists: that those who suffer from an illness cannot transcend their individual perspective. Susan Sontag 1933-2004. and Susan Sontag 1933-2004. A.I.D.S. and its metaphors. 1990., *Illness as Metaphor ; and, AIDS and its Metaphors*, 1st Anchor Books ed. (New York: Doubleday, 1990), 183 p.

<sup>56</sup> Of course, as the growing literature on the role of money in influencing expert opinion shows, many experts have vast interests.

<sup>57</sup> Susan Sontag 1933-2004. and Susan Sontag 1933-2004. A.I.D.S. and its metaphors. 1990., *Illness as Metaphor ; and, AIDS and its Metaphors*, 1st Anchor Books ed. (New York: Doubleday, 1990), 183 p.

perspective can contribute to fuller accounting of the subjective, as well as objective, aspects of an issue.<sup>58</sup>

Communicating the experience of living with stigmatized conditions may be most effective when presented in personal narratives that do not distance the emotional aspects. While classic deliberations would not admit emotional testimony on the grounds that it does not reflect the rational articulation. Since factors such as empathy and sympathy add informational value distinct from verbal expression, they should play a role in deliberation.<sup>59</sup> For example, Michael Neblo has argued in favor of expanding the deliberative ideal to include emotional expression. Hiding emotion behind reason does not enhance deliberation. Rather, displaying emotions can serve as an indicator of the strength of one's own preferences and for other deliberators, can communicate the importance of an issue.<sup>60</sup>

In contrast to the classic deliberative ideal that excludes self-interest or (interestedness in general) from deliberations, recent approaches to deliberative theory have argued for the legitimacy of expressing self-interested claims on the grounds that individuals are sources of self-legitimizing authority. In such types of deliberations, partiality must be laundered into

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<sup>58</sup> Ibid.

<sup>59</sup> See W. R. Neuman, *The Affect Effect : Dynamics of Emotion in Political Thinking and Behavior* (Chicago: University of Chicago Press, 2007), vi, 453 p.

<sup>60</sup> Michael Neblo, "Impassioned Democracy: The Role of Emotion in Deliberative Theory," working paper, Ohio State University, 2010. See also Norman Daniels, *Justice and Justification: Reflective Equilibrium in Theory and Practice*, vol. 22, Cambridge, U.K.: Cambridge University Press, 1996.

rational arguments.<sup>61</sup> To be sure, this demand for reasons serves a purpose: the success of translating self-interest into arguments whose principles reasonable people can agree upon can serve as a test of the soundness of those ideas.<sup>62</sup>

Finally, in contrast to a reasonable fear that including stakeholders will distort resource allocation decisions, it should be noted that partial views need not be incorrect views (though they are likely to be an incomplete view). Applied to health resource allocation, this means that the partial perspective that defines the stakeholder need not lead to demands for a disproportionate share of resources.<sup>63</sup> Given that partiality is an intrinsic part of activism and certain types of advocacy, an advocate may doggedly pursue a given position or cause while still remaining clear about the “objective” importance of the problem.<sup>64</sup> In cases of stigmatized

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<sup>61</sup> Jon Elster critiques the view, implicit in classic deliberative theory, that rules constraining the expression of partial argument will improve outcomes. He rejects the view that “the need to couch one’s arguments in terms of the common good will purge the desires of all selfish arguments.” James Bohman and William Rehg, *Deliberative Democracy : Essays on Reason and Politics* (Cambridge, Mass.: MIT Press, 1997a), xxx, 447 p.

<sup>62</sup> In a 2010 group-authored paper, Mansbridge et al declared that self-interest was wrongly excluded from the ideal of deliberative democracy. The authors claimed that there exists a moral value in pursuing self-interest in deliberation. In contrast to the classic deliberative ideal, certain forms of self-interest appear justified, even when deliberating about public policies and public resources.

<sup>63</sup> I am grateful to Jane Mansbridge for helping to clarify this distinction between the distorted partiality and the partiality of advocates, which may be incomplete but need not be inaccurate. Interview with Jane Mansbridge, March 2012.

<sup>64</sup> Of course, I do not deny the possibility that the common fear held by impartial skeptics would hold: that stakeholders would insist that their disease has a much greater importance than it does and therefore demand that it receive higher priority than is warranted. Rather, my goal is to

conditions, the partiality of the activist or advocate may be necessary to promote social justice, while traditional deliberation would simply support the unjust status quo.

### 3.2.3. Conclusion

The goal of this section has been to detail the ways in which partiality can enhance, thus opening the conceptual door for more consideration of how best to design a real-world deliberation that aims to capture the good and minimize the bad features of partiality. Partiality can serve, not only as a source of potential bias, but also as a corrective to bias. In some specific cases, such as stigmatized conditions, the partial perspective can help point out otherwise neglected dimensions of a topic and thus help lead to an appropriately impartial response. This “no conflict” situation means that the contrast between partiality and impartiality is sometimes misdrawn. Since partial claims can dovetail with mutually justifiable claims, they can pose less of a threat to good deliberation than classic deliberative theory might suggest.

More fundamentally, partiality *will* persist despite any theoretical or practical attempt to define the deliberative ideal as a search for the common good. Trying to expunge it is an exercise in futility. At the same time, the persistence of partiality need not undermine the deliberative enterprise. If the goal is to strengthen deliberations, acknowledging and channeling the power of partiality has a better chance of promoting good deliberation than clinging to an idealized notion of impartiality. Thus, articulating the ways that partiality can enhance decision-making offers a conceptual counterpoint to the skeptic’s kneejerk exclusion of stakeholders.

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highlight the fact that partiality and correctness are separate concepts that may occur together or not.

Partial perspectives are neither all good nor all bad: they can enhance or distort deliberation. The key question remains: how can we create deliberative processes that balance the valuable aspects of impartiality and partiality in applied settings such as real-world deliberative settings? Whether or not the positive effects of partiality discussed above will obtain in any given deliberation is contingent on a variety of empirical concerns. This challenge is the topic taken up in Section 3.

### **3.3. From Theory to Practice: Stakeholders in Real World Deliberations**

This section turns to the real-world implications of the previous sections' theoretical claims: first that partiality will always be in play, both in theory and certainly in practice, and secondly, that partiality can hold value for deliberation, provided certain conditions obtain. If these claims are correct, then attempts to exclude partiality by excluding stakeholders may impoverish deliberation by emphasizing the risks and ignoring the benefits of their inclusion. Yet the implications for real-world deliberative design remain ambiguous. An impartialist might concede that partiality can have epistemic value: canvassing a wide range of partial perspectives will illuminate more facets of a topic. Yet risk that partiality may lead to problematic bias remains.

In light of these lingering concerns, the principal task of this section is to translate the normative claims about the value of partiality in Section 2 into the empirical realm. Since we do not know exactly how to ensure that the benefits of stakeholders outweigh the risks, the salient question becomes: what conditions will encourage stakeholders to participate as well as possible? To explore this question, I present a hypothetical scenario: Mexican Ministry of Health-run series of deliberations on how to update the clinical guidelines and budgetary allocations for mental health. Although the specifics of different groups and different national and political contexts will vary between cases, this schematized illustration serves to ground the previous theoretical discussions in real world concerns.

For each class of concerns, I specify concrete proposals or tentative interventions possible institutional interventions that can support those stakeholders in making the best contribution they can. I note where the data remains sketchy and ripe for future research. For those interested

in incorporating stakeholders of stigmatized diseases into deliberations in countries without strong history of such, this section details a few ideas about what to consider.

Given the incomplete state of knowledge on this topic, this discussion cannot be a full defense of stakeholder participation or a guaranteed recipe for their successful inclusion. The discussion of possible concerns can be neither exhaustive nor definitive. Nevertheless, mapping these problems and benefits will help inform a more nuanced discussion of the merits of stakeholder participation in the context of real world priority setting. This preliminary work sets the stage to maximize the probability that in the future, deliberation designers will have more concrete tools to ensure that the benefits of stakeholder inclusion outweigh the risks. While research remains nascent on this subject, the ultimate goal will be to develop empirical guidelines and policy recommendations.

### *3.3.1. Hypothetical Case: Mexico Updates Its Public Mental Health Coverage*

Imagine that officials at the Mexican Ministry of Health need to update the mental health coverage in the country's basic health insurance plan, Seguro Popular. In the past, such decisions were made among experts and policymakers. Yet a few Ministry officials believe in democratic participation and would like to see decision-making include citizens and stakeholders. One ethically minded minister proposes inviting a relatively well-known Mexican mental health advocacy group to participate in the deliberations. In his mind, he sees the boost in legitimacy that including patient advocates may give to whatever final allocation decision is reached. The



invitation is extended. At this point, both the mental health advocacy group and the organizers of the deliberation in the Ministry of Health have some decisions to make.<sup>65</sup>

*3.3.1.a. What format should the deliberation follow to promote useful participation from non-expert stakeholder groups?*

Imagine that the group of mental health patients advocates sits down at the table with representatives of conservative psychiatric professional associations. The two groups may clash at first. Instead of engaging in deliberating over the issue, each side becomes more and more entrenched. In such cases, the choice of format for the deliberation may improve or worsen the chance of valuable stakeholder participation. Here the core issues are how procedural norms govern and manage the deliberation itself, and how those processes may influence how stakeholders participate. What is needed is a certain amount of impartiality from our deliberative processes in order to allow the safe incorporation of partiality into the process.

The dominant and persistent source of resistance to stakeholder inclusion is the concern that powerful, well-financed stakeholders will hijack, or even bypass entirely, any official deliberative process to secure funding for their own cause. In the United States for example,

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<sup>65</sup> Some may note that many of these decisions are non-deliberative. Most deliberative theorists agree that deliberative processes require non-deliberative decisions. Substantive choices must be made about the design and plan of the deliberation and not every decision can or should be reached through deliberation. John Parkinson et al., *Deliberative Systems : Deliberative Democracy at the Large Scale* (Cambridge: Cambridge University Press, 2012), x, 193 p.

patient advocacy organizations dedicated to breast cancer and heart disease, have leveraged their much greater resources to lobby for their cause in ways less-funded groups cannot.<sup>66</sup>

One concern is that self-selection will lead to “representational distortion,” a phenomenon in which the voting bodies may not reflect the population at large. Regardless of how stakeholders are recruited, it is likely that some self-selection will be in place. A health-specific concern in selection is that the least sick stakeholders may be the most able and willing to deliberate. This distribution of the ability to deliberate may vary by disease category. For some disease areas, like cognitive disabilities, these differences separate people as permanent features of their identity. For other diseases, such as HIV, differences in impairment may be progressive so less sick people may be at earlier stage. Thirdly, differences in sickness level may be probabilistic, such as how severe a case of measles or influenza. In the former case, we may be more concerned about having a range of views that represent the mild to the most severe forms of cognitive disabilities.

*3.3.1.b. How will the stigma against mental health affect deliberation and how can it be mitigated?*

One key question is whether mental health advocates will be able to express their partial perspectives in the face of opposing views from pharmaceutical representatives, physician groups and Ministry of Health officials. A related question is whether those groups will be able to see past the stigma

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<sup>66</sup> See Susannah Leigh Rose, *Conflicts of Interest among Oncology Clinical Trials Investigators and among Patient Advocacy Organizations, and Patient Preferences and Health Care Disparities*, 2010), vii, 116 leaves.

Stigma permeates many aspects of health decision-making: problem identification, advocacy, discrimination and societal and budgetary neglect. By definition, stigma dehumanizes individuals or groups.<sup>67</sup> Moreover, stigma and social status seem to have more than an additive effect: those with initial low status will be more affected by a stigmatized disease than those who initially had a higher status. The “double burden” of having a stigmatized disease as well as fewer predictors of social status, results in a compounded injustice in the deliberative space. Common biases toward the stakeholders can undermine the persuasiveness of an argument.

Secondly, the complicated and multidimensional nature of stakeholder identity makes a simple categorization difficult (yes, you are a stakeholder or no, you are not). Any one person can have multiple sources of partiality: professional advocate, a family member, a paid advocate for others and a semi-professional expert.<sup>68</sup> Just as socially mediated understanding of personal characteristics determined the reception of a jury member’s opinion, so too will the source of stakeholder identity influence, not only how one speaks and what one believes, but also how the other deliberators receive and respond to those opinions.<sup>69</sup>

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<sup>67</sup> Nicolas Rüsch, Matthias C. Angermeyer and Patrick W. Corrigan, "Mental Illness Stigma: Concepts, Consequences, and Initiatives to Reduce Stigma," *European Psychiatry* 20, no. 8 (12, 2005), 529-539.

<sup>68</sup> I am grateful to mental health advocate Mark Zanger for this insight. Interview with Mark Zanger, June 2013. Some countries have separate forms of deliberations for citizens and stakeholders. The categorical blurriness described here highlights the difficulty of such divisions, though they may be necessary for smooth functioning. Where boundaries are blurry, a certain level of flexibility in institutional design, where feasible, may be useful.

<sup>69</sup> Recall, however, that this paper defines stakeholder narrowly to include only non-expert stakeholders with a personal vested interest. To be sure, some advocates may care deeply about

Stigma may also lead to self-sabotaging behavior patterns in the deliberative process. Jury studies indicate that individuals of low social status may self-censor, meaning that they remain silent or misrepresent their true beliefs, when deliberating with jurors of higher educational background. A similar process may arise in health-resource settings: some patients' silence may reflect their internalization of social stigma. Such shame- or despair- based silence or self-censorship will likely be impervious to normative contentions, such as arguments that sufferers' partial perspectives carries moral and epistemic weight.

Our group of mental health advocates may face additional difficulties in deliberating effectively due to their own condition. The ability to engage in deliberation, or even self-advocacy, varies according the nature of the illness. For example, cognitive impairments may render some individuals unable to advocate for themselves.<sup>70</sup> In addition, stigma can affect influence directly. In fact, the socially contagious nature of stigma means that those associated with a highly stigmatized disease may receive the same level of condemnation or neglect as the stigmatized group itself. As Mark Zanger, a mental health advocate as well as a parent of a child with severe cognitive disability, argued that in the United States, families “are often treated as if they suffered from the same condition as the family members for whom they are advocating.”<sup>71</sup> In other words, medical decision-making processes often unwittingly reflect and perpetuate stigma.

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the topic, but not be personally affected by the condition, such as clinicians concerned with their patients' treatment or passionate advocates who became mobilized through learning of an issue.

<sup>70</sup> Interview with Mark Zanger, June 2013.

<sup>71</sup> Ibid.

Deliberations with stakeholders should help to mitigate stigma as well as stigma's negative impact on policy. By forcing deliberators to interact face-to-face, the deliberative process can improve communication by humanizing different groups to each other. To give a non-health example of successful stigma minimization through deliberation, Fishkin describes a deliberation he ran in Romania, with his deliberative polling group. The topic concerned whether or not to provide certain social benefits for the socially maligned Roma people. When polled prior to the deliberation, many of the majority deliberators expressed negatively biased views toward the Roma. During the face-to-face deliberations, Roma individuals provided face-to-face testimony that refuted the common negative stereotypes about the Roma. (For example, one woman described how many hours a day she worked, which counteracted the stereotype of laziness among the Roma). Post-deliberative polling suggests that this deliberation helped dispel negative stereotypes and majority voters expressed decreased support for policies that would harm the Roma.<sup>72</sup>

Another method to minimize bias and the effect of stigma is to “blind” deliberators from knowing the source of certain information. This technique has long been used in scientific experiments (“double-blind” studies) to minimize bias. Recent initiatives have translated this practice into the courts.<sup>73</sup> When expert witnesses testify, they usually know which side has

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<sup>72</sup> The example raises the question of whether the public's preferences should always be respected. Counterfactually, had their opinions not changed, any discriminatory policies would remain unjust because of substantive notions of justice. See James S. Fishkin and Peter Laslett, *Debating Deliberative Democracy*, Vol. 7 (Malden, MA: Blackwell, 2003), 234.

<sup>73</sup> Robertson, “Blind Expertise.”

contracted their services, which can bias their testimony. The proposal to blind experts to who hired them—the prosecution or defense—predicts that removing this information may yield more balanced testimony. Translating this idea from scientific experiments and trials to deliberations offers the hope that blinding may play a similarly neutralizing role. Deliberators could review testimony given from a source who does not know the issue under discussion, which would remove the risk that either side simply presents evidence in its favor. This technique would also minimize the risk that deliberators would discount one another’s testimony because of its source.

*3.3.1.c. How will the relative social status of the mental health advocates influence the deliberative process?*

The severely mentally ill also tend to be at a relative disadvantage in terms of social status. Yet classic deliberative theory has not armor against the influence of social power, because deliberation was defined as a process free of power relations. However, social power differentials that exist in the real world remain in the deliberation.

For example, in a classic study of the social dynamics of jury deliberations, Sanders found that the very same argument had much greater impact among the other jurors when spoken by a white male rather than a black woman. Another study found that in groups of mixed social status, the higher status individuals had more influence; the lower one’s social status the lower the influence. Even more troublingly, this “status bias” persisted even when the higher status

individual had much less knowledge than the lower status individual.<sup>74</sup> In fact, the lower status individuals doubted their own opinions more in such scenarios.

One way to combat this problem is by establishing “enclave deliberations,” defined as homogenous deliberative groups. Such enclaves may minimize the risk of group polarization by eliminating differential status as a factor.<sup>75</sup> Similarly, a study of a priority setting exercise with Medicaid recipients showed that it is morally, psychologically and practically easier for individuals to make difficult tradeoffs and cuts about their own benefits than to do so with ‘rival’ groups (those competing for the same resources).<sup>76</sup>

Another concern is that deliberation unfairly privileges the already socially privileged—those endowed with what Sanders has called the “material pre-requisites for deliberation.”<sup>77</sup> These prerequisites include not only the skills of verbal fluency, but also background knowledge of the issues, and their ability to marshal the resources to develop and defend arguments with others who may be more informed.<sup>78</sup> Thus, low status individuals will be at a disadvantage long before

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<sup>74</sup> Cass R. Sunstein, "The Law of Group Polarization," *Journal of Political Philosophy* 10, no. 2 (2002), 175-195.

<sup>75</sup> Ibid. There are also cautions against tokenism and for support in A4R. See the checklist at the end of Norman Daniels, “Fair Process in Patient Selection for Antiretroviral Treatment in WHO’s Goal of 3 by 5,” *Lancet* 366, no. 9480 (2005).

<sup>76</sup> This also raises the key topic in moral philosophy about interpersonal vs. intrapersonal decisions. Thomas M. Scanlon, *What We Owe to Each Other*, Cambridge, Mass.: Harvard University Press, 1998.

<sup>77</sup> Lynn M. Sanders, “Against Deliberation,” *Political Theory* 25, vol. 3 (1997).

the deliberation itself, because they will be less equipped to prepare for, and thus to excel in, the deliberation.

One response to this problem is to guarantee a measure of procedural impartiality to the deliberation, so that no one group can dominate. Providing a common set of background materials to deliberators may mitigate these imbalances. For example, Fishkin's deliberative polling presents each individual with the same set of materials to study prior to deliberating.<sup>79</sup> In the short run, procedural interventions may help to counteract the tendency to discount opinions from lower status individuals. For example, the clinical guidelines committees hosted by the National Institute of Clinical Excellence in the United Kingdom allow stakeholders to participate by giving testimony and recommendations during consultations. To ensure that their voices are not overshadowed by experts, the committee reserves special time in the agenda for the patient representative to speak.<sup>80</sup>

Another plausible way to counter the conservative tendencies of deliberation may be to actively encourage, rather than just tolerate, a wider range of argumentation styles. Such a procedural

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<sup>78</sup> Interview with Diana Pinto, July 2009.

<sup>79</sup> Note, however, that in the case of Fishkin's deliberative polls, all the deliberators are non-experts, so there will likely be fewer interpersonal differences in technical knowledge than in policy-determining deliberation. In the case of Colombian citizen councils, they included both pharmaceutical representatives and indigeneous group representatives with little formal education. Asserting rules about what informational materials can play a role will be more important in the latter scenario. Interview with Diana Pinto, July 2009.

<sup>80</sup> Kreis and Schmidt, *Public Engagement in Health Technology Assessment and Coverage Decisions: A Study of Experiences in France, Germany, and the United Kingdom*, Vol. 38, 2013), 89-122.



change would acknowledge the epistemological gain to be gained by widening the forms of ‘moral contention,’ to use Anderson’s phrase.<sup>81</sup>

The choice of ideal final outcome is a procedural feature that can influence how well a deliberation works for stakeholders. In an influential critique of deliberation, Sanders argued that this goal of consensus undermines deliberative theory’s own commitment to equality. Rather than facilitating the expression of non-majority views, consensus chasing results in a ‘dangerous deafness to dissent’ as non-majority views are ignored or not expressed in the rush to agree. For example, she notes the US feminism the singular focus on common ground among women—”we are all women.” This focus on commonality served to silence discussion about ‘dimensions of difference’ between women, most problematically along the fault lines of race and class.<sup>82</sup> Regardless of whether Sanders is correct in her diagnosis of feminism, the key insight is that the choice of final outcome will influence the deliberative processes itself. For example, if the mental health advocates faced the seemingly immutable disapproval of the majority, they may not press their case as fervently.

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<sup>81</sup> Anderson, “The Epistemology of Democracy.”

<sup>82</sup> See Mansbridge et al., *The Place of Self-Interest and the Role of Power in Deliberative Democracy*, Vol. 18 (Wiley-Blackwell, 2010), 64-100.

### *3.3.1.d. Will the deliberations promote social justice in health policies?*

The participation of mental health advocacy groups in deliberations about how to update Mexican mental health policies is not merely a technical matter. Given the longstanding neglect of mental illness as a public policy issue, the effectiveness of the non-expert stakeholders to advocate for greater equality in coverage for mental health as physical illnesses carries moral importance.

Deliberations may exacerbate, rather than ameliorate, differences of opinion between groups. As elsewhere, the empirical evidence points in several directions. Some studies indicate that pre-deliberative differences in opinion do not soften after deliberation. As Sunstein notes, the fact that deliberating itself causes group polarization is a “striking but largely neglected statistical regularity.”<sup>83</sup> Greater polarization seems to occur more frequently with controversial topics than less heated topics.<sup>84</sup>

Theorists have also expressed concern that deliberation may actually serve to undermine the momentum of social movements. As Thompson hypothesized, perhaps “when opponents seem less like enemies, mobilizing to bring about their defeat seems less urgent.”<sup>85</sup> In support of this hypothesis, one study of Colombian observers of stakeholder health councils noted that citizens

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<sup>83</sup> Sunstein, *The Law of Group Polarization*, Vol. 10 Blackwell Publishers Ltd., 2002), 175-195.

“The Law of Group Polarization.”

<sup>84</sup> See Kevin M. Esterling, Archon Fung and Taeku Lee, “How Much Disagreement is Good for Democratic Deliberation? the California Speaks Health Care Reform Experiment” (Working Paper, 2010).

<sup>85</sup> Thompson, “Deliberative Democratic Theory.”

who participate in citizen fora were less likely to protest regarding social injustices.<sup>86</sup> While still unconfirmed, the impact of deliberations on general social mobilization for justice remains a key issue to for future research. Stakeholders should be aware of this possibility when weighing the merits of participating, especially in deliberations with powerful opponents.

Since resources often flow to ‘squeaky wheels,’ any comparative disadvantage in deliberating can create a vicious circle: silence reinforces and enables policymakers’ neglect of their condition.<sup>87</sup> Unjust policies may result from the lack of effective advocacy strategies, making effective and stakeholder inclusion in deliberations all the more important as a matter of social justice.

### *3.3.1.e. How will the political or national context influence the deliberation or its impact?*

The mental health advocates may be wary of participating in the Mexican clinical guidelines update because of the country’s history of non-democratic policymaking. For example, one cross-country study found that special interest groups—even when they did not participate in citizen councils—nevertheless engaged in repeated attempts to strategically influence the deliberation in their favor. A related concern is that governments will convene “sham

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<sup>86</sup> M. Mosquera et al., "Strengthening User Participation through Health Sector Reform in Colombia: A Study of Institutional Change and Social Representation," *Health Policy and Planning* 16 Suppl 2 (Dec, 2001), 52-60.

<sup>87</sup> Another case where lack of advocacy leads to policy neglect is that of rare diseases. The small number of people with the disease limits stakeholders’ ability to mobilize *en masse* for self-advocacy. Of course, the prospect of profits has led pharmaceutical companies to take up the cause. See the Costa Rica Gauchers example from Safra Presentation: Stephen Heuser, “One Girl’s Hope, a Nation’s Dilemma,” *Boston Globe*, June 14, 2009.

deliberations,” designed only to present a façade of legitimacy behind which government can continue to set policies as arbitrarily as ever. In such cases, the stakeholders will have to judge whether or not the exercise is authentic and secondly, whether they can benefit from participating (e.g., they may gain valuable media attention even if there is little hope of reaching their ideal outcome).

Less nefariously, the timing and publicity surrounding a deliberation will affect its impact. In Germany, Hendriks describes how a 2001 citizen council on genetic diagnoses attracted virtually no attention because simultaneous “formal, expert-dominated fora” overshadowed it. Moreover, the council’s conclusions went nowhere because it had not “been situated to have any impact on prominent expert advisory committees.”<sup>88</sup> Such extra-deliberative factors play a powerful role in shaping the impact of deliberations. To maximize the impact of a deliberative process, the planners can be sure to time the release of its report so as not to conflict with major events.

### *3.3.2. Conclusion*

This section turned to the real world implications of the theoretical arguments in favor of partiality developed in the first two sections. In the real world, Habermas’ vision of the “unforced force of the better argument” does not always win out. Rather, socially mediated, and more troublingly, morally irrelevant, factors can undermine stakeholders’ successful

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<sup>88</sup> Carolyn M. Hendriks, "When the Forum Meets Interest Politics: Strategic Uses of Public Deliberation," *Politics & Society* 34, no. 4 (December 2006, 2006c), 571-571-602.

participation at the individual deliberation and extra-deliberative levels. Race, gender, level of stigma, political context: all these factors and more affect the impact of stakeholders in the deliberation and, in turn, how the deliberation affects the societal response. The most accurate conclusion is that the answer is not a simple yes or no. By providing a set of concrete problems and detailing how they may affect a deliberation, this section has clarified what issues may arise when stakeholders participate in deliberations.

### **3.4. Toward a Robust Account of Non-Expert Stakeholders in Deliberations about Health**

Whether or not to include stakeholders in public deliberation for priority setting raises a host of ethical questions. The central threat is the risk that the deliberation would be co-opted by special interests. This paper has argued that the applied problem of whether to include stakeholders in public deliberations can be illuminated by framing it in terms of the perennial problem of whether there can be morally admirable partiality in moral reasoning. Stakeholders represent partiality, their participation in deliberations conflicts with deliberative theory's traditional emphasis on impartiality. I have argued first, that impartiality alone cannot and should not be the guiding standard of deliberation and secondly, that partiality can enhance deliberations.

In cases of priority setting for stigmatized health conditions, non-expert stakeholder participation may actually facilitate the capacity of deliberative processes to produce sound health policy, as well as providing the normative value of enhancing the process' fairness and legitimacy.

Excluding stakeholders entirely eliminates both important sources of information as well as the intrinsic value in allowing interested parties to speak on their own behalf. By extension, the partiality of stakeholders offers sufficient potential value to deliberation to make trying to overcome the risks they also bring worthwhile.

Several broad conclusions about deliberations and stakeholders can be drawn from this study.

First, deliberations can paradoxically perpetuate the kinds of social and economic power imbalances and strategic behavior that it was designed to correct. If public deliberations with partial individuals are to play an influential role in guiding real world health policymaking, future research needs to examine how these intricate social, political and economic factors influence

real deliberations, as well as what forms of innovative mechanisms or contextual factors might neutralize the more pernicious ways that stakeholder participation may derail deliberations.

Secondly, a “one size fits all” approach for deciding whether to include stakeholders in deliberation is impossible. A variety of factors—personal, procedural, topical, political—will shape whether stakeholder participation in priority setting processes carries more benefits or risks. Some contexts will lend themselves more fully to stakeholder participation than others. The best choice of how to populate a deliberation will vary between countries, or even within national regions, depending on factors such as, the nature of the public policy issue, socioeconomic inequality and the citizenry’s historic relations to the state. Therefore, more socially and historically grounded studies of deliberative practice will be a necessary next step.

These risks will require more careful specifications of the norms that guide the deliberative process. Third, further knowledge is required to make strong empirically tested recommendations about how best to structure deliberations with stakeholders. The future practical challenge becomes how to develop ethically grounded and concrete guidelines for managing that participation. The growing interest in inviting stakeholders into policymaking makes the need for research all the more urgent.<sup>89</sup>

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<sup>89</sup> For example, the recent founding and goals of the new US government agency, the Patient-Centered Outcomes Research Institute (PCORI), make this need to discern best practices around stakeholder participation more urgent.

### *3.4.1. Methodological Objections*

Some might object to either the methodological approach or the substantive recommendations developed here. One limitation is that many of tentative proposals outlined in Section 3 hinge on incompletely untested empirical claims. Further, no best practice yet exists for many aspects of deliberative practice. To illustrate this problem, consider that recommendations about how to structure a deliberation can lead to wildly different outcomes. For example, as Sunstein acknowledges, “enclave deliberations,” can simultaneously be a “potential danger to social stability...and a safeguard against social injustice and unreasonableness.”<sup>90</sup>

A second methodological objection is that many of the empirical studies used as proxies for deliberation involve topics far enough from deliberation to make them poor proxies. Indeed, drawing conclusions about deliberation based on related studies requires both interpretive imagination and caution. The rich literature on negotiation and bargaining would appear to be highly generalizable to deliberations, since the processes appear nearly identical. Recall, however, that the normative ideal of deliberation as impartial and free of interests or power has long been defined precisely in contrast to negotiations, defined by their interest- and power-based nature.

Despite these methodological caveats, valuable lessons can still be drawn from these topically related social-scientific studies. Jury studies still offer close examinations of how socially diverse groups discuss and reach a verdict. Similarly, studies of expert witness at trials demonstrate how certain individuals are socially designated as “experts,” a topic very close to the issue of when

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<sup>90</sup> Sunstein, “The Law of Group Polarization.”



stakeholders may be granted epistemic authority or not.<sup>91</sup> Finally, historical work can reveal when and why deliberative bodies actually engaged with the public versus serving as covers for “elite manipulation” or to legitimate state interests.<sup>92</sup>

### *3.4.2. Concerns about Deliberation as Force for Social Progress*

Despite the potential for deliberations to improve social justice through stakeholder participation, democratic deliberation will never be the sole solution to all societal problems. There is a body of literature that argues activism is a better path for those interested in fighting injustice than deliberation. Philosopher Iris Young has argued that deliberative democratic theory should primarily function as a critical theory that indicates where systems have gone wrong, not a guide to action. Deliberative theory should keep a distance from democratic practices. One cannot simply apply deliberative theory to develop institutional mechanisms. Similarly, even the participation of outsiders cannot challenge unjust practices because the communication between all participants will be tainted by “hegemonic generalizations about the way that social relations and the world work.”<sup>93</sup> Since common discourse is itself the product of structural inequality,

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<sup>91</sup> Christopher Robertson and David Yokum, "Effect of Blinded Experts on Mock Jurors' Assessments of Credibility and Verdicts in Civil Trials," *Available at SSRN 1884765* (2011).

<sup>92</sup> See Matthew R. Keller, "When is the State's Gaze Focused? British Royal Commissions and the Bureaucratization of Conflict," *Journal of Historical Sociology* (2013), n/a-n/a.

For a contemporary example of the elite nature of some commissions, note that the Presidential Commission on Bioethics is composed entirely of professionals selected by the Executive Office. All current members have PhDs: <http://bioethics.gov>.

<sup>93</sup> Iris Marion Young, "Activist Challenges to Deliberative Democracy," *Political Theory* 29, no. 5 (Oct., 2001), pp. 670-690.

even those who are low end of totem pole will share the basic principles. Only activism, Young argues, can “make us wonder about what we are doing, to rupture a thought” rather than deliberation’s focus on weaving an argument.”<sup>94</sup>

Activists should be suspicious of more formally inclusive processes. Given background inequality, de facto exclusion may persist despite formal inclusion. Sham deliberations may allow the powerful forces to perpetrate continued injustices. Money, speech and power all help determine who is able to deliberate in first place. Activists say we should continue working from the outside because continuing to participate in corrupt processes will only give them undeserved legitimacy. This critique refers to what Fung has called “deliberation’s dark side.”<sup>95</sup>

Yet deliberative practices and activism are not mutually exclusive. Indeed, despite such arguments, democratic deliberative theory has always bridged theory and practice. The fact that stakeholders in deliberations have limited power to change the broader context does not discredit the entire effort. Since overhauling the whole system is not realistic, stakeholders seeking justice can divide their efforts between deliberative processes that advance inclusion in the realm of policy while others can continue to strive for justice from outside the deliberative process.

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<sup>94</sup> Iris Marion Young, "Activist Challenges to Deliberative Democracy," *Political Theory* 29, no. 5 (Oct., 2001), pp. 670-690.

<sup>95</sup> Archon Fung, "Deliberation's Darker Side: Six Questions for Iris Marion Young and Jane Mansbridge," *National Civic Review* 93, no. 4 (Winter2004, 2004), 47-54.

### *3.4.3. Directions for Future Research*

The current state of knowledge about deliberative processes cannot address what a fuller defense of the role of partial perspectives of stakeholders would look like. Ultimately, the goal should be to develop a richer understanding of what conditions support the successful participation of stakeholders and other partial actors in deliberations. Such empirical research should lead to the development of clear guidelines about where and why and how to include stakeholders so as to maximize the potential benefits of their participation and minimize the risks.

First, it is not sufficient to claim that stakeholder participation offers normative and empirical benefits. The argument that stakeholders can improve deliberative process does not imply that all stakeholders have equal ability to participate well in deliberations. Many patients will not be sufficiently informed about the technical aspects of policymaking. Other stakeholders will be unable to channel the temperamental civility or epistemic openness to consider other points of view (a problem not exclusive to stakeholders).<sup>96</sup> Future research should study how different groups participate specifically in deliberations so as to improve selection of stakeholders.

The conceptual understanding of deliberation should continue to be expanded beyond impartiality. In practice, this expansion would mean allowing emotional expression, personal narrative and other forms of testimony. Including such non-traditional forms of argumentation

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<sup>96</sup> Note that none of the virtues of partiality detract from the special technical knowledge of the sort expressed by experts.

would open the door to stakeholder participation. Once deliberations tolerant of such partiality are established, they must be subject to rigorous research so that knowledge can accumulate.<sup>97</sup>

Another area for future research is the social dynamics between deliberators. Acknowledging the lack of such guidelines, Jane Mansbridge has called for “minimal norms of civility” for the non-speaking roles of deliberation: moderators, listeners and facilitators.<sup>98</sup> A good facilitator should be able to start with a poorly articulated idea and draw out the speaker’s intent. Admitting stakeholders as deliberators as well as the free expression of partial reasons would place a greater burden on listeners to evaluate the merits of the claims, ex-ante constraints on persons or reasons. Thus, theoretical attention should be paid to considering the appropriate epistemic stance of *listeners* as well as speakers in deliberation.

Given growing worldwide interest in stakeholders in deliberations, future work should focus on the development of strategies—such as ethical and procedural guidelines—to support stakeholders’ valuable participation in the deliberative space and to minimize its risks.

Particularly for newly democratizing countries, public deliberation with stakeholders represents a potentially transformational relationship between citizens and the state. At stake in examining deliberations is the potential for countries to develop fairer policies, increase public trust and support that government exists for all the people, not just a select few.

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<sup>97</sup> See Diana C. Mutz, "Is Deliberative Democracy a Falsifiable Theory?" *Annual Review of Political Science* 11, no. 1 (06/01, 2008), 521-538.

<sup>98</sup> Mansbridge, Jane, “Deliberative Polling as the Gold Standard,” *Good Society* 19, no. 1 (2010). Mansbridge’s paper deals with Fishkin’s deliberative polling.

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